

Dee's Desktop in collaboration with
Writer's Best Editing Services and The Power of the Dream, Inc

The Binnacle

Charting Your Own Course



The Binnacle is the case in which the ship's compass is kept. It allowed mariners to determine their direction even if clouds obscured their usual astronomical cues such as the North Star.



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Welcome to The Binnacle. We are a lifestyle and resource newsletter where disability is centered and celebrated as diversity.

Here the challenges that come with living fully as a person with a disability are embraced with gusto, joy, and humor.

Embark with us!



The Binnacle

STAFF

Aldea LaParr

Publisher/Writer

Nessie Siler

Editor/Writer

Anna Cunningham

Consultant/Writer

Contributors

Donna Spears

Haley Solomon

Michelle Appleby

Phillip Woodward

Kayla Davis

Darcy Hildreth

Aimee Leveque

Jessica Leveque

Wesley Siler

Wendy Orzel

Michael Orzel

Janice Fitzgerald

John Fitzgerald

Bryan Dooley

Dave Owen Yall

Notes from the Publisher—Dee's Desktop

by Aldea LaParr -

With our first Issue behind us, I wanted to thank EVERYONE who has read, liked, and shared with others. The reception has been amazing! It's been a dream of mine to have this kind of publication, but I never had the courage to start. When I found out that Anna and Nessie shared the dream, it then became a reality.

The Binnacle has turned out to be way more than a publication. We invited people that we know to submit pieces and with that we built onto existing relationships and created new ones. By assisting those who want to share their story, we are building confidence in each of us.

Although living with a disability is not always convenient and manageable, we will always try to highlight our successes while tackling the topics that we all need to be aware of. Please let us know if there is a topic that you would like us to share or explore.



You can access ALL issues at TheBinnacle.net



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Publishing

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DeesDesktop.com

Finding True Love

By Donna Spears

I've met able bodied men in my lifetime. However, they wanted to use me or abused me. I thought I'd never meet anyone who would love me for me. Advocacy groups taught me that I didn't have to settle for less than what I deserved. I prayed to God to send me a man that would know Him and love me for who I am.

Well, my mother passed away April 12th 2011. On April 10th, I received an email from a gentleman from an online dating site. He sounded nice in the email. We decided to communicate through email for a while because he was in North Carolina and I was in Louisiana. Then my mom passed away so Michael decided to call me and the most wonderful thing happened, when I heard his voice a soothing sensation came over me.

We decided to talk on the phone from then on. Talking for hours at night and on the weekend we got to know one another quite well. He made me feel so happy, I couldn't believe it! He decided he would come to Louisiana to meet me. When he came to the airport I fell head over heels for him. He stayed a week.

A year and a half later, Michael asked me to make a lifelong commitment to him and I said yes. So in July we had a commitment ceremony just like a real wedding. I was in the process of having cornea transplants so I couldn't live with Michael for three years while I recovered. On July 4th 2016 I took my independence and moved to North Carolina where I am living my dream life. Michael is so good to me I love him more and more every day .



Donna Spears



I was born in South-west Louisiana. I live in Richlands NC, I've lived North Carolina for five years. I have been an advocate for thirty years, helping people that can't advocate for themselves. I have two degrees in Psychology and I have Cerebral Palsy living with my life partner Michael McGilton.



My Employment Journey

By Michelle Appleby

I started high school in 1987 in a little military town in Northern NY (not far from Canada). I had just come out of 3 yrs of homeschooling when I decided to attend public school again. Obviously turning 14 is a milestone for a lot of teens. That's the age you can start working - but with restrictions. Having a physical disability made it more "interesting" for me since things back then weren't the same as they are now for people with disabilities. The ADA wasn't put into legislation until July of 1990, when I was a senior. However, I was taught to volunteer, which helped me gain job skills. The Job Training Partnership Act of 1982, which helped "disadvantaged" people, provided on the job training and I was able to gain employment pretty quickly. ([1982 Job Partnership Act](#)).

My first job, I worked for a non-profit doing reception and data entry. That started my employment journey of working for many nonprofits in my area, mostly working in areas of personal interest and experience for me - fair housing, disability rights, advocating for kids in foster care. I served 4 years as a policymaker on the Developmental Disabilities Planning Council. Fast forward to today, I currently have worked for Habitat for Humanity for the last 2 years. These are all areas I had personal experience volunteering in. A lot of times people with disabilities lack any kind of job skills.

Volunteering can open doors for you for many reasons. It helps you gain on the job training in a specific area and may also allow you access to training that the agency or establishment you volunteer for is offering. Volunteering puts you in contact with people in your community who may have an opportunity for you on their staff. In 2004, I wanted to get back into the employment field after going through a divorce in 2001 and having my second daughter in 2004. There was a position available on the Board of Directors for our local Independent Living Center. I submitted my name and I was elected to my first term on the Board. In 2006, while on the Board, I learned of a program called Partners in Policymaking. This is a national program for parents of school aged children with disabilities and adults with disabilities. ([Partners in Policy Making](#))

I applied and was accepted to that program for 6 months in the state of New York, where I reside. Ironically, about the time my daughter started school, a position opened up, in 2007 on the Independent Living Center's staff, for a Systems Advocate



Michelle Appleby lives in Northern NY with her two daughters. She is a landlord and currently working as an Independent Living Advocate for the Northern Regional Center for Independent Living.



It allowed me to utilize all the information I had learned through the Partners in Policymaking Program about programs and services, best practices and working with the media, along with my personal knowledge of maneuvering the system in order to make changes for people with disabilities, through the different levels of government, that improve their quality of life. It put me in a position to cultivate relationships with legislators and policymakers that were pertinent in making some of those changes. As a result I played a part in the Help America Vote Act - providing input on the accessible voting machines. Eventually, In 2009, I was one of 25 people in New York State to receive the Excelsior award for Excellence from the New York State Assembly and I was asked to serve on The New York State Developmental Disabilities Planning Council, which initially funded the Partners in Policymaking program. I was appointed as a policymaker by Governor Patterson and I served 1 term. It may have been luck - or the fact that I have a big mouth and strong opinions - but I'm grateful for those opportunities.

Personal experience on various topics sometimes is more valuable than what you may learn in a training or text. Not everyone with a disability is by the text or medical model. I'm a firm believer that everyone has something to offer. As a person with a disability, I had personal experience with navigating our social care and disability service system. Whether it be for financial reasons, healthcare, transportation or affordable accessible housing. I spent 2 years in foster care and eventually was adopted - which prompted me to become an advocate for kids in foster care. I lived in subsidized housing for 14 years, dealt with lack of accessible housing - I was a fair housing advocate. I experienced pigeon holing, discrimination, and the lack of accessible housing. My kids were exposed to drugs and crime as a result of being reduced to living in subsidized housing because there was a shortage of accessible, affordable housing for people with disabilities. How things are required to run and how people are personally affected by these systems and programs are 2 entirely different things. Use those personal experiences to change things for the future!

Michelle Appleby and Aldea LaParr are seen here at an ADA Celebration in Lowville, NY. Both worked for the Northern Regional Center for Independent Living as well as being council members of the NYS Developmental Disabilities Planning Council.



Personal experience on various topics sometimes is more valuable than what you may learn in a training or text.

Not everyone with a disability is by the text or medical model.

We would love to hear from you!

We are looking for feedback and writers!

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The Recreation Man

When it came to reaching out to someone to submit an Accessibility Photo, we did not have to go far. We reached out to Phillip who brightens a room with his excitement of life and always wanting to learn what is available out there and accessible. This is his first of many submissions to come!

NCCDD Systems Change Manager Philip Woodward loves hearing about, finding, and experiencing accessible places in North Carolina. While previously working as the Access Specialist at the North Carolina Division of Vocational Rehabilitation Services from 2009-2015, he compiled the *ACCESS North Carolina* travel guide that lists tourist attractions across North Carolina and includes information and ratings related to their accessibility to people with various types of disabilities or accessibility needs. Woodward, who is Hard of Hearing himself, visited many of these places with a person with a mobility or other type of disability to photograph the individual experiencing the site and to give the management feedback about ways to improve accessibility for all visitors. Anyone who is interested in learning more about accessible places to visit in North Carolina can like and follow "Access North Carolina" on Facebook, and anyone who is looking for something accessible or who finds something accessible and wants to share the experience can e-mail Woodward at accessnorthcarolina@gmail.com

Anyone who is interested in learning more about accessible places to visit in North Carolina can like and follow "Access North Carolina" on Facebook.



facebook





In 2010, Grandfather Mountain opened a Top Shop building with an elevator that provided access to the famous Mile High Swinging Bridge for people with mobility disabilities. Prior to 2010, people had to climb 50 steps from the parking lot to access the bridge (fourth photo). But the elevator in the Top Shop led to a pathway that went right across the bridge, so visitors no longer had to use the steps to have the opportunity to cross the bridge and enjoy the spectacular 360-degree views of the Blue Ridge Mountains! Pictured are Brittany Eggers pushing Tammy Perkins across the bridge in the spring of 2010 and Luke Wilcox with his parents and doing a media interview at the official opening of the Top Shop building on June 21st, 2010.

Learn more at www.grandfather.com/visit/plan-your-visit/accessibility/



The Importance of Better Transportation Resources for People with Disabilities

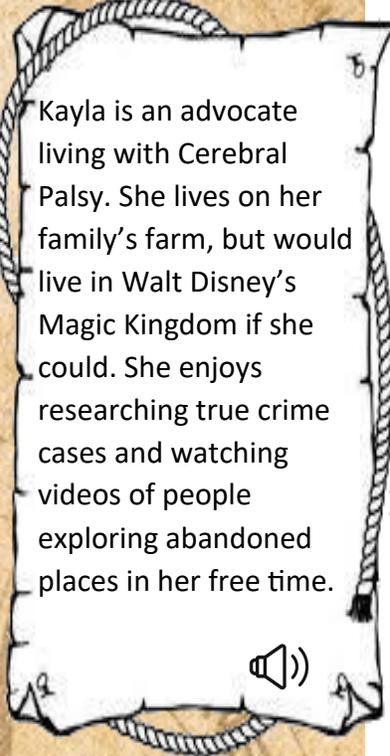
By Kayla Davis

I've been trying to write this for a long time. I know what I want to write, but I couldn't find the motivation to write it. Honestly, I have been struggling a lot lately. I am not content with my life right now and I don't know how to fix it. My hope is that if I share my story enough, it will eventually lead me to someone who can help me get the resources that I need in order to accomplish my goals.

My biggest obstacle right now is transportation. I have spastic Cerebral Palsy, which means sudden noises or movements cause my muscles to spasm. This makes driving unsafe. If you cannot drive, it can be almost impossible to find employment or do fun things. This reality is very challenging to cope with. I want to be someone that others look to when they need an example of a person who overcame adversity, and turned their dreams into reality despite their obstacles. My fear is that if better transportation options don't become available, I will just be seen as someone who became a victim of the circumstances of their disability.

I completed my Associate's degree in Paralegal Technology, and am now working toward a Bachelor's degree in Communications. My dream is to open a tanning salon that sells cupcakes and hires people with disabilities. If I can't do that, I would like to travel the country and share my story and encourage people to embrace their opportunities and abilities. Again, though, I cannot drive, and I am not independent without my power chair. So your typical Uber or taxi is not an option for me. The resources for transportation available to those of us with disabilities are simply not enough. They are only used for medical appointments, which leave no option for people who can't transport themselves and wish to have a job. The other issue is that the current transportation options are extremely unreliable. One of the other self-advocates on our advisory board has shared his frustrations with our current transportation options (or lack thereof). He has shared that he has had to stay at his doctor's office for hours because Mountain Mobility has failed to pick him up. This is not acceptable.

I've always known the importance of employment. It's my goal to be as physically and financially independent as I can. Ideally, I would move out and have a caregiver that takes me to work every day. However, as time passes, I realize how incredibly unrealistic this is because most caregivers are not reliable. So the more practical option would be an Uber that is power wheelchair friendly.



Kayla is an advocate living with Cerebral Palsy. She lives on her family's farm, but would live in Walt Disney's Magic Kingdom if she could. She enjoys researching true crime cases and watching videos of people exploring abandoned places in her free time.



As I said before, life is expensive, especially when you have a disability. I've heard people say, "You have it made because you get SSI and Medicaid." This is simply an ignorant way of thinking. SSI may only be enough to cover a couple of bills, and Medicaid is very strict when it comes to what they cover.

Before I got primary insurance and before I got a trailer to transport my power chair, my manual chair was falling apart, but Medicaid refused to cover a new manual chair because they had paid for my power chair. I was also told that Medicaid would only pay for 2 pool therapy visits, which isn't going to do any good. My point is a job that earns good money and/or has decent insurance is crucial when it comes to getting the extra care and equipment that a person with a disability needs.

Having a disability also means having to miss out on fun things, unless you have a good support system. Even if someone has a great support system it's not practical to rely solely on that because many of our family and friends have full-time jobs or may be getting too old to help us get where we need/ want to go. For me, it's just important to be independent without feeling like a burden on my family, even though they have never made me feel like one. There are lots of fun things I hope I get to do. I would like to go back to Nashville and take pictures of the murals. I would like to go back to Chattanooga and see the butterflies and penguins again. I would like to go to an East Mississippi Community College football game (the school from Last Chance U), and I would like to go to Wilmington and see the One Tree Hill filming locations. They also have a convention twice a year where you can meet the actors, take pictures and get their autographs. A handicapped accessible Uber would also make it easier for me to attend advisory board meetings.

I hope this article sheds some light on the need for more adequate transportation options for people with disabilities.



My point is a job that earns good money and/or has decent insurance is crucial when it comes to getting the extra care and equipment that a person with a disability needs.



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I'm Not Waiting for Help

By Nessie Siler

Writer's Best Editing Services began in November 2013. I had been a client of North Carolina Vocational Rehabilitation on and off for several years. They had been quite helpful in helping me get through school, and with some needed equipment purchases. Before I had begun my business, they had previously alerted me to an opportunity as an at-home customer service representative. I applied and got the job, but sadly, it did not work out. I was not prepared to be, in effect, completely on my own in a job I had never done before, without any meaningful access to supervisors or a job coach, no matter how much I begged my counselor for one. I departed the job after three months. I was demoralized. I had never failed at anything before. I was so angry at myself.

About six months later, I found myself ready to try again in my job search. This time, Vocational Rehabilitation barely spoke to me. I couldn't get so much as an email returned. I was taken aback by this. I thought it was me and they were just done. Very well, I wouldn't bother them.

As a 2012 Partners in Policymaking graduate, I learned through research that VR counselors in North Carolina typically had about 100 clients each. I also learned that the Vocational Rehabilitation Report for 2011 detailed that they had been able to successfully transition only about 10% of their clients to employment that year. I calculated that my odds of success in job seeking and procurement lay elsewhere. I had always loved words and stories. I was so proficient in spelling as a child that my parents would come to me if they couldn't spell certain words, because they knew I would be able to. I was nine at the time. And there wasn't an English class I couldn't pass, from elementary school through college.

Nessie Siler is a freelance editor and advocate with an Individualized Bachelor of Arts in Disability Studies from Goddard College in Plainfield, Vermont. She lives in Manteo, North Carolina with her husband Wesley, their four month old kitten, a worrying Netflix habit and more books than she could read in three lifetimes.





So I decided that I would look into editing. I then read everything I could find anywhere I could find it on the subject of editing. I learned there were several different types of editing, and that editing differed from proofreading. Proofreading is a service one can offer in addition to editing, but it is not the same thing. Also, I learned that academic editing was a different animal altogether. I learned attention to detail was crucial to the editing process and that a good rapport with the clients you work with is a must. They trust your judgment, and you will be working with them for the length of the project, which can last weeks or months. The learning process involved in being a good editor never ends. It's like continuing education for any other job. The best part for me is working with words. Also, I work from home. Everything I need can be accessed via my computer. My commute to work is about 20 feet. For a person with a disability - who cannot drive - this is a godsend.

I joined the Editorial Freelancers Association and hung out my shingle. I have seven years professional experience editing everything from novels to newsletters and I am on the staff of two publishing companies. I have also augmented my skills through transcription as an independent contractor. I work with independent authors, students, and businesses. Every day is interesting.

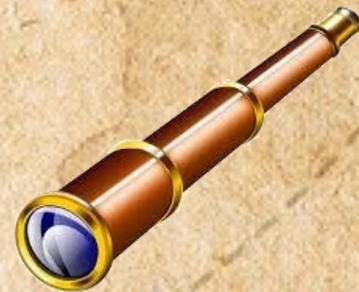
Services are good to have. However, sometimes what's available through services and what you need or want are two different things. It's okay to go a different route if you feel the need. Don't be afraid to take something you love or are good at and turn it into something on your own. Anything can happen if you work at it.

P.S. About a year after I started my business, I got a phone call from a young intern at VR wanting to know how my job search was going. I told her that after such a long time with no contact from them I no longer considered myself their client. And I told her about Writer's Best Editing Services, which I had created without them. My counselor showed up at my front door the next morning to close my case and offer help. The poor man. There wasn't anything left for him to do! I almost felt sorry for him.



Writer's Best Editing Services

Nessie Siler
Owner/Editor



Don't Stop Believing

By Darcy Hildreth

So many people have asked why we left Boston for New Bern..... In my typical Boston sarcasm, I always want to say "witness protection" just to watch the look on people's faces as they try to figure out if that's true or not (it's not! – at least if it was, I wouldn't tell you – haha)

Anyway, the real reason was, although he had an incredibly rocky start in life, our son Brendon managed to go to school and against all odds, get his high school diploma. He had surgeries that kept him home, illnesses and appointments, not unlike many other kids with "special needs" (I don't like that term, we all have something that needs accommodations, some are just more visible than others). Upon graduation, Brendon wanted to go to college. Living in Massachusetts, I would have thought that it would have been so easy to get the accommodations he needed. We found quite the opposite was true! He was too "disabled" for MassRehab and too cognitively there for the Department of Developmental Delays. Neither agency wanted to step up and make sure he got what he needed. We also had one college tell us they couldn't make the accommodations we were looking for – I asked them if they had heard of the ADA? Sometimes you just get beaten down enough and you can either become very angry from fighting all the time or just give it to God. We chose the latter.

We had looked into Easter Seals and adult services for people with disabilities. There was one in Vermont (too cold), Virginia (not feeling it) or North Carolina (possibilities).... My husband didn't want to be too far from the beach, as we lived close by in Massachusetts. We started looking at New Bern. When we came down, we were greeted with "What can we do to help you?" Wow, was this a refreshing question!! Finally someone wanted to help!!

Quite honestly, it was the hardest thing I've ever done, leaving home of 50+ years and everything we knew. But like Abraham in the Bible, we trusted God and took a leap of faith.

I'm a wife of 37 years, mother of 3, An avid coffee drinker, Rescue and rehome cats, over-tired most of the time, Can't keep up with the laundry. Very real about life, blessed with many wonderful friends. Strong faith in our Lord Jesus Christ and couldn't imagine a day without Him in my life, we have some great conversations.

I think I have a pretty kind heart and try to look for the best in everyone and that people play fair. Shoes are optional in life.



Brendon enrolled in Craven Community College in New Bern and graduated with 2 associate degrees and 3 certificates. He is currently enrolled at East Carolina University (ECU) getting a Bachelor's degree and is set to graduate in May of 2022!!

While this has been an incredibly emotional journey, we have been met by many people who want to help, who return our phone calls and who genuinely care about his welfare and education. What an honor. There is no way to describe the feelings we have watching our son, who wasn't supposed to live past day 2, getting prepared to graduate from college.

Don't give up!! To borrow a phrase from a Journey song: "Don't Stop Believing." Keep the faith!



Darcy and Brendon



"...it was the hardest thing I've ever done, leaving home of 50+ years and everything we knew...

...Don't give up!! To borrow a phrase from a Journey song: 'Don't Stop Believing.' Keep the faith!"



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Dee's Desktop

Aldea LaParr
Owner/
Webmaster

Aldea is a website designer who actually got her Bachelor of Arts in Technical Theatre. She lives in Princeton, NC after living in upstate NY for most of her life. She is Mom to three sons and Meme to two grandchildren. She loves to travel and try new cuisines.



A New and Unique Family

By Aldea LaParr

High school was so difficult because up to this time my family moved on an average of every 2 years due to my father's being in the U.S. Navy. Not only is it hard on children to have to be uprooted from their home and friends, but as a child with a disability being assigned to new teachers, I found myself spending too much time trying to prove to them that I belonged in their class.

When my guidance counselor called me in his office to help plan my life after high school, I had absolutely nothing prepared. He asked me all the typical questions regarding college. Still a blank. He then asked me "Well, what did you like about high school?". I told him that I loved working backstage on the High School Musicals and being involved in Community Theatre. He came back with "You can go to college for Technical Theatre.". The other factor was my SAT scores being very low. I think he really wanted me to go to school because he found a school with the program that I wanted AND accepted my scores.

I ended up attending St. Edward's University in Austin, TX. The only downside was it was 2500 miles from home. I would not be a weekend home trip and would be stuck there until the semester ended. My dad drove me all the way down, unloaded my gear at the dorm and left.

After a week of living alone because my new roommate never showed up, I call my mom begging to fly me home. She said, "I told you that you can't come home until the end of your first semester." I knew we could not afford it.

After three weeks I called home again. But this time I was calling to say, "Thank you!". By this time, I had made so many new friends in the Theatre department and most of them were from out of state and the were stuck there too. We were a family. And I was blown away by how everyone accepted my disability, even the Professors! We were all dealing with something or another. Gay, straight, black or white, we were together all the time. We all had the same goal, The Show Must Go On!



What is Inclusive Theater of WNY (ITOWNY) and Why Do We Do What We Do?

By Aimee M. Levesque, PhD

My beginning on this inclusive theater journey began many years prior to the Inclusive Theater of WNY (ITOWNY) even being a blip on my radar. It was when my daughter, Jessica, who has autism, was in school. She certainly had her ups and downs within various school districts (which is enough material for a series of other articles, indeed!) but her biggest challenge always seemed to be her desire to “feel and be normal” (her words not mine) as well as be included in school with her non-disabled peers. And sitting in a classroom with them was not the inclusion that she was looking for. Rather, she wanted to PARTICIPATE with them in the things that were fun and social; dances, special events, and theater.

The first two were easy – she could buy tickets to dances and events and just simply show up – although oftentimes there was a significant amount of fear in doing this and a staff person from the school or her disabled peers would hang out together and not mingle with the other students. The latter, though, theater, seemed to be a significant issue. Jessica could get an audition but somehow, she would always end up as part of the ensemble; hanging out at the back of the stage, typically with other disabled peers, who snapped their fingers and clapped in a jubilant way for the non-disabled actors who were always the stars of the shows. It always baffled me. Jessica had this incredible knack for memorizing lines from shows and movies, word for word. She also studied facial expressions and body movements and although she might not necessarily understand why someone was making a certain face or moving a certain way (deficit area of Autism), she was able to nail the expressions as though she had been studying the art of acting for centuries. And I don't mean one or two movies or shows. She memorized hundreds or dare I even say thousands of roles that she one day hoped to play. Still, the opportunities were limited at best.



Aimee M. Levesque



Aimee is the Founder, Executive and Artistic Director of Inclusive Theater of WNY. She received her PhD from the University of Buffalo and her dissertation focused on empowerment through the arts for persons with disabilities. She also has degrees in English, Library Science, and Criminal Justice. Aimee grew up in Charlotte, NC and now resides in Western New York. She is a big fan of horror movies and pizza and her daughter is the reason behind all that she does.



What is Inclusive Theater of WNY (ITOWNY) and Why Do We Do What We Do?

So I thought, “We can’t possibly be the only ones dealing with situations like this, especially since there weren’t disabled people cast in any of the plays that we were seeing (in AND outside of school). We have to do something about it!” I am also not the type of person who waits for opportunities to happen – I am a firm believer that if the opportunity doesn’t exist, it’s your job to create it – so ITOWNY was born.

Everything we do at ITOWNY is developed to be mindful of the needs of artists from varying ability levels and backgrounds. However, we *never* alter our programming, we alter the environment. Artists who come to ITOWNY are not incapable of doing anything, we merely make opportunities possible for them to showcase their talents. Sometimes we may have to make accommodations, for example, if someone needs extra time to learn the script, we extend the number of rehearsals we have. If the stage is inaccessible, we make it accessible or we find an alternate location to perform. If someone has challenges remembering lines, we extend rehearsal by a few weeks. In one of the shows we performed, an actor had some challenges with memory retention and no matter the amount of rehearsal time he had, it was difficult for him to remember his lines. So we printed the script and placed it on props that he used throughout the production. No one saw the script pages but him and even if the pages had been seen, the quality of the work he produced kept your eyes focused on him – not on the props. Both he and the show were a hit!



I am also not the type of person who waits for opportunities to happen – I am a firm believer that if the opportunity doesn’t exist, it’s your job to create it – so ITOWNY was born.





Strengthening relationships with the arts community, especially while we could not physically be together, was (and still is!) so very important to us and these weekly events helped us to do so.



COVID-19 was the catalyst for a giant shift in how we create art – we had to go from physical spaces to virtual ones and we did it with enthusiasm and pride! When the world shut down in early 2020, we began a weekly online speaker series on Inclusion in the Arts. For six months, we met every Saturday night and had some great guests that discussed everything from accessibility to diversity and inclusion and how they connected and were important to the Arts. Strengthening relationships with the arts community, especially while we could not physically be together, was (and still is!) so very important to us and these weekly events helped us to do so.

Our speaker series eventually morphed into monthly online play readings that feature local and national playwrights and still continues today! Each month, we select a playwright (sometimes we do a call for plays, other times writers reach out to us) and we do a reading of three of their short plays. We hold regular virtual auditions for actors and the great thing about that is that you do not have to live near ITOWNY's offices to participate; everything is on Zoom! An actor needs only to work hard and commit to the performance. There are so many opportunities for those who might be interested! Additionally, we have had the opportunity to participate in different facets of the arts since being online. The past two years we have been a part of the Easterseals Disability Film Challenge, creating short films that are shared on a global platform. This year, we are also working on virtual art festivals, writing groups, telling our stories, and digital art – all online! We are having an absolute blast and ALL are welcome to participate!



We would love to hear from you!

We are looking for feedback and writers!

[Contact us Here!](#)



As you can see, the advantages to being online are many; despite the chaos in the world around us, we have stayed connected as a company. New people have learned about ITOWNY online. We have continued to evolve and expand our art opportunities. We are expanding our reach beyond the walls of WNY. And we have also realized the importance of a hybrid model of performing arts and how it will still be important as we move into the future.

We have also learned about the importance of resilience. Art reflects our humanity and it invites us to think about how we engage with one another in society. This unusual time has given us formidable opportunities to create art, build community, cultivate mindfulness, and to foster conversations in varied ways.

Opportunities for EVERYONE to create, grow, perform and to learn and share with one another need to exist. In creating these opportunities, it is our hope that we would learn not only about our differences and how vast our differences are but also learn about those things that tie us together; those same, unifying things that are part of the HUMAN experience.

ITOWNY celebrates the beauty of diversity. Diversity makes us richer as people and helps us and the world around us to grow. When each person is able to contribute their particular gifts and share their personal experiences and stories, the world becomes a better place to be in.

We do what we do out of love. And we have only just begun.



Find out more about Inclusive Theater of WNY (ITOWNY):

Email: inclusivetheaterofwny@gmail.com



Opportunities for EVERYONE to create, grow, perform and to learn and share with one another need to exist.



Why I'm a Part of Inclusive Theater of WNY (ITOWNY)

By Jessica Levesque

All my life, I wanted to be an actress, dancer, entrepreneur, and singer. For a long time, I was told that I couldn't do any of these things because I was disabled and I wouldn't amount to anything. This negativity came from people in the school district and in the special education system and unfortunately, some people out in the world.

Inclusive Theater of WNY (ITOWNY) makes me feel like I'm contributing to society. When I am participating, I'm not seen as a person that has a disability I am seen as someone who is an actor; someone who has been performing for almost 10 years. I am seen as a human being and not as a label that society has put on me. I'm very grateful every day that a company like this accepts all people and lets you be who you truly are.

One of the best experiences I ever had with ITOWNY was when we did our first staged performance, "And Where Will You Put the Things You Save?" by Baroness von Smith. I played the role of Erica; a roller derby chick with autism who was bio-hacked with a magnet in her finger. She lived with her supportive brother and his partner and the play explored the themes of choices, independence, and breaking stereotype barriers. What I loved about the play is that for a person who used to be a roller derby chick (me!), it was great to put on some of the old gear and just remember the fun times I used to have. My co-stars, Steve and John, were really great to work with. Both have performed in Buffalo Theater for years and they were kind to me and there was a lot of mutual respect. They also taught me how to remain calm and how not to be "too too nervous" for live performances. I also loved performing in front of live audiences on a professional stage in an actual theater. It was a super cool opportunity.

Since then, I have played the role of Titania in William Shakespeare's *A Midsummer Night's Dream* and have performed in ITOWNY's short play festivals. Since going 100% online, I have also participated in a global film challenge, was in a music video for a local band, and have acted in ITOWNY's monthly short play readings. It is important for me to keep doing the work that I love so that I can continue to improve my skills as an actor.

In closing, my advice for those who want to participate in the arts (or in anything for that matter!) is, don't let anyone tell you what you can't do and never let anyone tear down your dreams. Get out of your comfort zone and be your true authentic self. There is only one you and your voice matters. So does your art. You are the pilot of your life so fly as high as you'd like to go!



Jessica Levesque



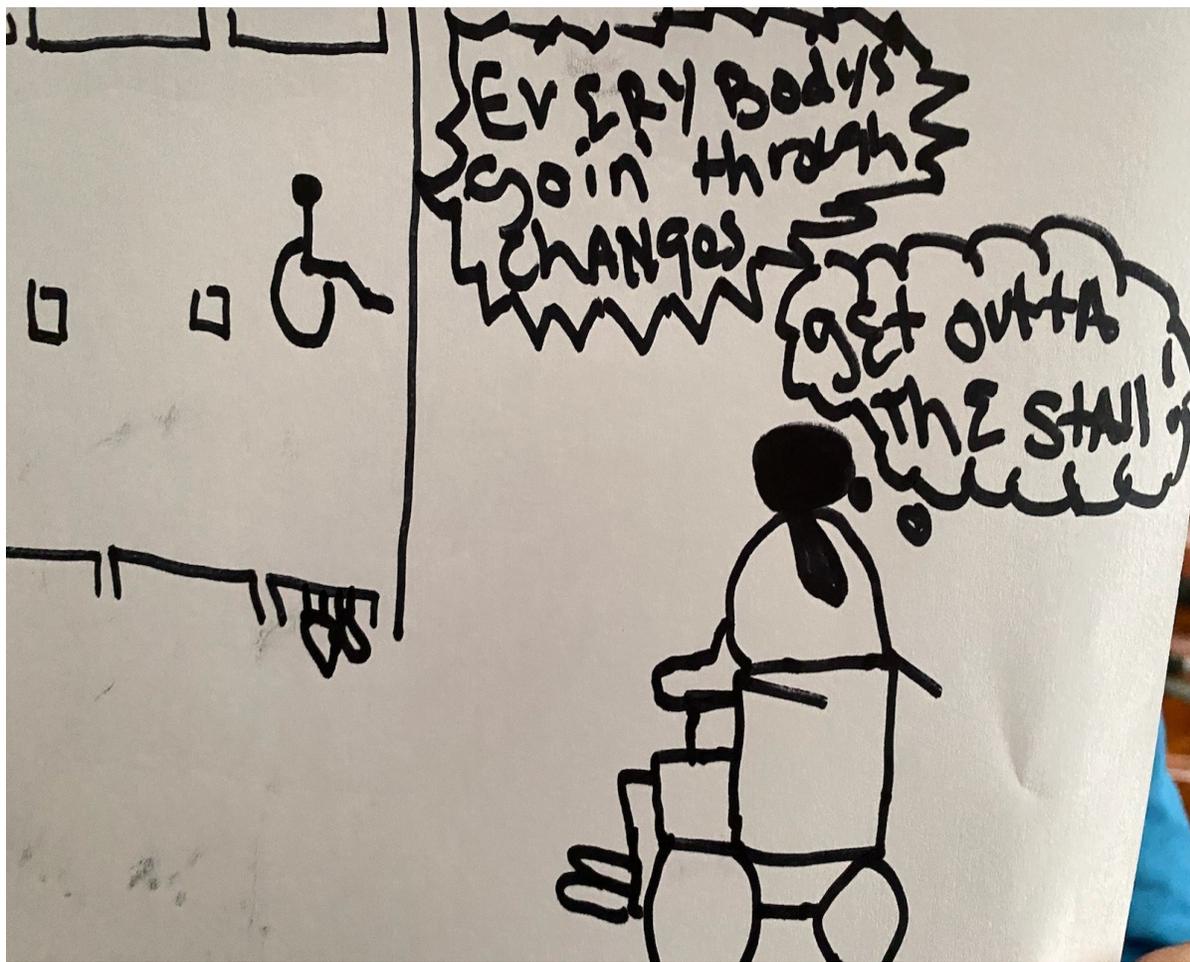
Jessica is an entrepreneur, dancer, singer, artist, and actor. She has lived in Western New York all of her life. She enjoys traveling, performing, and being a furmom to Binx and Waffles her two cats, and Wednesday, her Bichon Frise. She is also a huge fan of mobster, science fiction, and horror movies. Her favorite holidays are Halloween and her birthday.



Wesley's Take



"Tap, tappity, tap, ...Yeah this song is great! It will be perfect for the party tonight!"



"...Meanwhile, everyday needs going unfilled."

Wesley Siler is a comics enthusiast with a BA in Creative Writing from St. Andrews Presbyterian College in Laurinburg, North Carolina. He reveres Jim Lee, Neil Gaiman, and Todd McFarlane. He lives in Manteo, North Carolina with his wife and a rambunctious four month old kitten



The Savvy Advocate

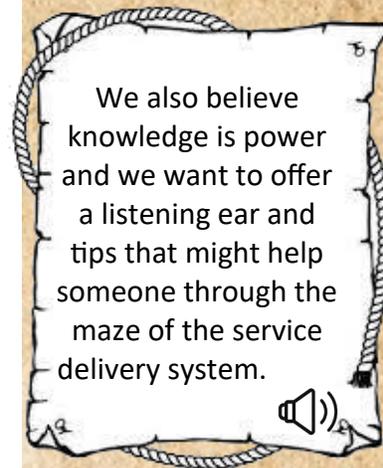
By Nessie Siler

The Savvy Advocate was born because my husband and I lost our health insurance. For a year. In that year, I searched frantically for an answer. (ABLE accounts were still brand –new on the scene. I didn’t know much about them. Special needs trusts cost more money to set up than the bequest that had gotten us kicked off the rolls in the first place, and surprise! We were in the doughnut hole for the Affordable Care Act). While I searched, I prayed nightly that we would not be visited with a need for emergency surgery. Thank goodness, we weren’t.

The way through our quandary became clear only because I was a member of the North Carolina Medicaid Long Term Services and Supports Stakeholder Engagement Group. At our very last meeting - figuring it was now or never - I asked to bend the ear of a friend who worked in the NC Department of Health and Human Services who was also a member of our group in an advisory capacity.

I detailed our plight in full, and she directed me toward the Medicaid program: Healthcare for Workers with Disabilities or H.C.W.D. As my husband and I both were (and still are) working, this seemed the best option to keep us insured. I learned later that N.C. was at the time under a Federal injunction to offer this program as an option to Medicaid recipients who might qualify for it. However; I had heard nothing about it from our Medicaid caseworker before our coverage elapsed. She only discussed it with me after I told her I knew about the program.

The Savvy Advocate is here because we know not everyone has the privilege of access to staff at DHHS. We also believe knowledge is power and we want to offer a listening ear and tips that might help someone through the maze of the service delivery system.





Why Do I Advocate?

Not because I have to
Not because I want to
But because of the willingness to belong.

Belonging to a society means having opportunities to learn, and to grow into activities.

Things that were once prohibitive for a person with a disability, we now have a right to participate in society because we are equal, yet different.

Some may see that people who do not fit the mold of normalcy should be relegated to the backseat of life, to pick up the leftovers of persons in front of them. I do NOT feel like this. I feel that everyone must have equal rights and have the right to belong. At times it may seem like it is out of spite and you may not agree with the choices that we make and the chances that we take, but that's ok.

This is why I advocate.

All that I ask is to be heard
It's not about being right
It's not about being wrong
It is the freedom to make choices
And to belong
It's ok to disagree
As long as I have the opportunity
Life is wonderful and free but it's up to us to make it so



© 2007 Wendy P. Orzel



Wendy Orzel lives with her husband Michael in Albany, NY. Wendy has been a very active advocate for so many while a council member of the NYS DDPC for 20 years.



Not "Mary Poppins"

I want to be seen
as a full human being
with all the joys
that it brings

I want to be touched
by a woman so much
that I will be able
to sing

but thus far
it did not happen
who we are
not "Mary Poppins"

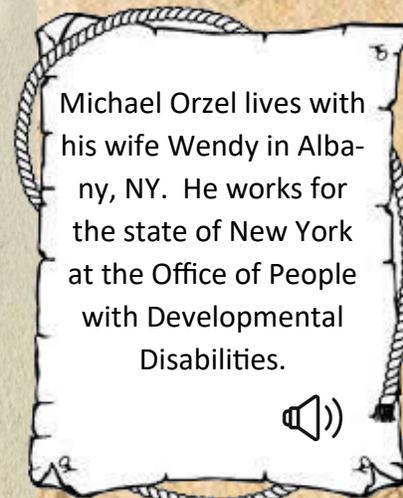
I want to be employed
because I am not a boy
and pay taxes
as any citizen

I want to be respected
so that I will not be neglected
from this race
I want to win

but thus far
it did not happen
who we are
not "Mary Poppins"



(c) 1983 Michael M. Orzel



COVID 19 and impact of eviction

By Janice Fitzgerald

For our family, the lifestyle changes brought about by COVID-19 were an adjustment. Self-isolating and physically distancing create a strange feeling after having almost daily contact with friends and family. It is a manageable compromise to preserve health and safety. It was unnerving making the first trip to the grocery store, and going to the pharmacy was even more uncomfortable.

In the spring 2020, we developed a rhythm to our days including chores, daily walks, and house projects. We've experienced a range of emotions during this pandemic, including frustration and loneliness at the loss of social opportunities. There have been times we felt a sense of hopelessness from the fear and vulnerability created by this virus. Sometimes there is boredom, but pauses and silence can be a respite. We follow the guidelines, doing only essential errands and avoiding crowded spaces.

Are there reactions? Certainly. We are grateful for our health; grateful most of our extended family have their jobs. We appreciated a beautiful summer and fall with fresh air and time to enjoy the outdoors with family and friends.

Since 2012, our son, John, who has intellectual and developmental disabilities, has lived independently in a small, but functional apartment not far from us. John needs assistance with managing his finances and we, John's parents, make sure his finances are stable. John could easily be victimized or taken advantage of. We help ensure the supports that John needs are in place and functioning to help him be happy and safe. We have advocated and helped him achieve as much independence as possible, yet we are the contingency when things go awry or when something falls through the cracks.

For me, concerns often revolve around issues ensuring John is secure and doing well. When possible, we plan in advance.

Living within a couple of miles of our home, John has been able to be part of our household as well as have his independence. Dinners together, and near daily conversations, afford a time for us to "check-in". We help each other as needed. John's two-day-a-week job ended in March when the college he worked at closed. He was one of the country's millions who lost their employment. Fast forward to August, and John is back to work, as long as college is in session.



Parenting John was the catalyst for a shift in my career from accounting to working to help other parents know they are not alone and to help other parents know they are not alone. There is healing and strength when a parent has another parent to talk to; who has experienced similar emotions. Knowing you are not alone helps a parent adapt to their new normal and helps a parent transition to being confident in their new roles and being proactive in advocating for their son or daughter.



John has limited outside contact with others, uses his mask when in public and spends time in public spaces only when absolutely necessary. John's social circle is often his family. He coped with self-isolation in his apartment by taking daily snowshoe walks when snow was still on the ground, and moved to hiking trails when spring arrived. Getting outdoors is healthy and John takes precautions to be a safe outdoorsperson. This includes being prepared for unusual or hazardous weather.

In May 2020, the **notice** arrived. The "notice" was the May 15 eviction notice that John found taped to his door indicating he was to be out of his apartment by June 30. "We recently came to the decision that we will be concluding our rental agreement as of the end of June – a month and a half from now." The eviction protection under New York State Executive Order pertains solely to non-payment of rent.

Who would evict someone when there is a pandemic with no rentals available or affordable homes for sale? Even if a home is for sale, imagine the scramble to pull resources together to purchase. How could we mortgage our home in 40 days? John had zero resources to apply towards a move or purchase. The eviction notice ended with the offer to provide a reference, if needed, for a new rental. In a note to me it was stated "we have appreciated John as a tenant, and we hope he has enjoyed his time here, and learned valuable lessons about living independently". Considering his landlord's comments to me, John was clearly a respectful tenant and was not being evicted for any untoward behavior.



John setting up his new mailbox

A week after the eviction, I saw a post for a manufactured home for sale. It is an area John likes and within a couple of miles of our home. We scrambled to put in an offer, with a down payment. We had to apply for a home equity loan on our residence to finance the purchase. Before retiring, we worked hard to get out of debt, and going into debt again was not something we planned to do. Working with a local bank, we were able to apply for and close on a loan. The closing on the home purchase was June 23. John has a new place to live with a beautiful yard and more space. He has stable housing. One fear that surfaced after receipt of the eviction notice was that John would need to move back to our home. It was a mutual fear as John enjoys his own place.



"We came to the decision that we will be concluding our rental agreement as of the end of June". The eviction protection during this pandemic under New York's Executive Order pertains solely to non-payment of rent.

We would love to hear from you!

We are looking for feedback writers!

[Contact us Here!](#)

From The Hold

Our experience is not unheard of for parents, and their sons or daughters with disabilities. They have supported them to be independent and self-directed, and many parents have helped their son or daughter pick up the pieces after a crisis like the eviction. Our experiences during the past few months are one example of the challenges parents of individuals with disabilities face their entire lifetime.

We consider it good fortune that this move worked out for John, but we will always be concerned about his future and how similar events might impact John when we are no longer here to help him. In hindsight, we knew it would be good for John to have stability in a home he could eventually own. The apartment was adequate, but did not have outdoor space. We knew a larger place with a yard would be a future goal. However, we have never been quick to make changes when things are working.

This experience has increased awareness of taking contingency planning more seriously. One important part is making sure we outline the many things that are in place for John by developing a communication tool that someone could use to help if we are not able to.

There are qualities and life experiences that helped us get through this. Tenacity, keeping a clear head and staying calm helped. Family members have knowledge of construction, repairs and inspecting buildings, and that was crucial in being able to move quickly on the purchase offer. Project planning and management experience helped map out to do lists and prioritize the work. There were several projects that needed to be completed before moving in. Identifying projects and setting up steps to accomplish them were part of the planning. Close proximity to where we live and where John lives helped.

Our goal, and the goal of every parent, for every child, is to see him or her in a good life, surrounded by a strong community of family and friends for support and encouragement. It is unfortunate that an unforeseen event caused us such turmoil. Despite the head-spinning suddenness of the eviction, we managed, and so did John, who proudly and lovingly mows his lawn and maintains his home. That is our joint success.

Our goal, and the goal of every parent, for every child, is to see him or her in a good life, surrounded by a strong community of family and friends for support and encouragement.



Backyard picnic

Janice, Doug and John Fitzgerald live in Lake Clear, NY which is located in the Adirondack Park. Janice's advocacy for individuals with disabilities included work at the Adirondack Arc, Parent to Parent of NYS, Parent to Parent USA and as a past member of the NYS Developmental Disabilities Planning Council. In his work for NYS, Doug assisted with and advocated for accessibility in recreation. As a Boy Scout Leader, he helped ensure scouts of all abilities were included.

Janice's contact jfitzgerald250@gmail.com



Hiking Mt. Marshall
9/2020

John Fitzgerald



Growing Up With Disabilities

Click the Picture of John to View his story.



We would love to hear from you!

We are looking for feedback and writers!

[Contact us Here!](#)



Dave Owen and Bryan Dooley

The Tale of Dooley and the D.S.P.: The D.D. Network



This adventure of triumph and tragedy, perseverance and posterity, and the search for a fruitful life began in early April of 2016. Bryan Dooley was in search of an assistant with the know-how and gusto to enrich and further his life and spread his story of inclusion throughout the land. Dave Owen, a native of the Camel City, who had recently sown and reaped live music industry seeds throughout the land, was ready for a new task. Dooley's Bat-Signal was illuminated brightly across the Facebook sphere and Dave the D.S.P. answered the call.

NC DSP Workgroup
Our Mission is to
increase and
strengthen the
NC DSP Workforce for
individuals with I/DD
in North Carolina.

To check out more
information at

The North Carolina
Direct Support
Professional
Workgroup

[\(NC DSP Workgroup\)](#)

facebook



After a quick meeting of the minds, it became apparent that both parties would benefit from each other's company. Dave-- being a novice in the disability rights realm-- had some experience with his previous employer who was a quadriplegic. After a rigorous crash course in all things Dooley, the D.S.P. was fashioned, and a total trajectory into this wonderful world would soon take flight.

Dave was nervous at first. His brute strength was something he didn't want to overpower Dooley. It took some time for Bryan's speech patterns to make absolute sense but once the D.S.P. ran his internal-transmodificalculator, Dooley's sequencing patterns made sense for dissemination across this land of liberty.

There were outings to Washington D.C., Baltimore, New Orleans, and all corners of the great Tar Heel State. The D.S.P. accompanied him to assist in transportation, nutrition regimens, bone and muscle tune-ups, recreational activities, social gatherings, canine domesticating, and superhero costume adornment. But most important in this equation is their Voltron-like synergy in the steadfast juggernaut of disability rights advocacy work they are committed to.



This story isn't without its share of sorrow and heartache. Dave the D.S.P. lost his father to a battle with cancer and found solace with his boss, Bryan. A few years later, Dooley lost his mother and his largest support system as well. Both members of the team grieved in their own way, but somehow built upon each other's loss and used each other to honor their respective earthly creators by carrying on the torch bestowed to them.

Dooley and the D.S.P. were born out of Dave's harebrained "Master Blaster" reference from the post-apocalyptic cinema masterpiece, Mad Max: Beyond Thunder Dome. It was a cartoon idea, and Dave found a comic book illustrator in Uruguay. He was receptive to the idea and thus began their fledgling comic book idea. Currently, the possibilities are limitless, and they are entertaining the idea as a playful and useful teaching tool for children of all ages. The shirts they created are a way to raise funds to put back into their pedagogy program and to create pamphlets, stickers, posters, etc. to pass out to children as educational materials.

Dooley and the D.S.P. are a completely unorthodox pairing, but have somehow made it work after 5 years. There is no reason to be "normal" because each and everyone in this world is wonderfully weird. Those are the types of people The D.D. Network wants to cater to. Be nice. Or else you'll be hearing from their very loud dogs.



Shirts are available at 533.houseofrodan.com.



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