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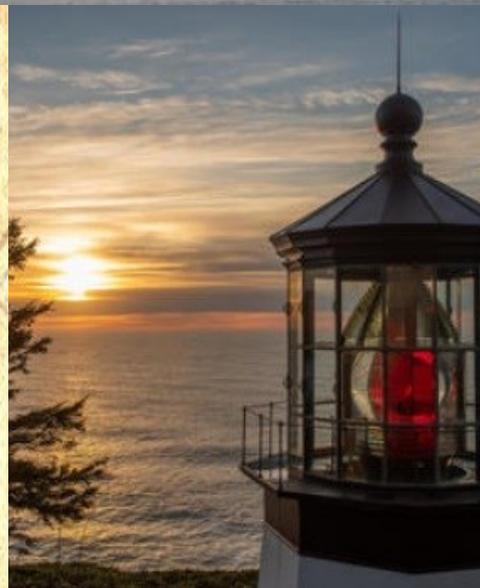
Winter 2022
Volume 2, Issue 1

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 re-
source 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

Chris Wylie

Phillip Woodward

Wesley Siler

Wendy Orzel

Notes from the Publisher—Dee's Desktop

by Aldea LaParr

We are entering our second year! Our third year as a team! I am amazed by the caliber of contributors we have had in just our first year. We have covered so many topics that we believe are timely and necessary as well as fun and inspirational. In this issue you'll find out more about The Binnacle's journey and the doors that we opened.

Our real push continues to be to reach out to all of our readers to invite all of you to share your story with us. We are looking for all kinds of content. Stories, pictures, drawings, and any kind of content that informs and inspires. Individuals, families, and professionals are welcome to submit content.



You can access ALL issues at TheBinnacle.net

Submit your content [Here](#)



Dee's Desktop
Publishing

Supporting Professionals with Developmental Disabilities



I believe that one of the most exciting things for me to come from the work that we are doing with The Binnacle is the opportunity to not only the hear stories from individuals with developmental disabilities but we are supporting professionals with developmental disabilities. All of our staff and regular contributors are individuals with developmental disabilities or family members. This process has brought out the best in ALL of us.

We want to encourage other Professionals with Developmental Disabilities to feel free to reach out to us to see how we may be able to help. We each have tools and strategies to share that may help you or the person that you are working with.

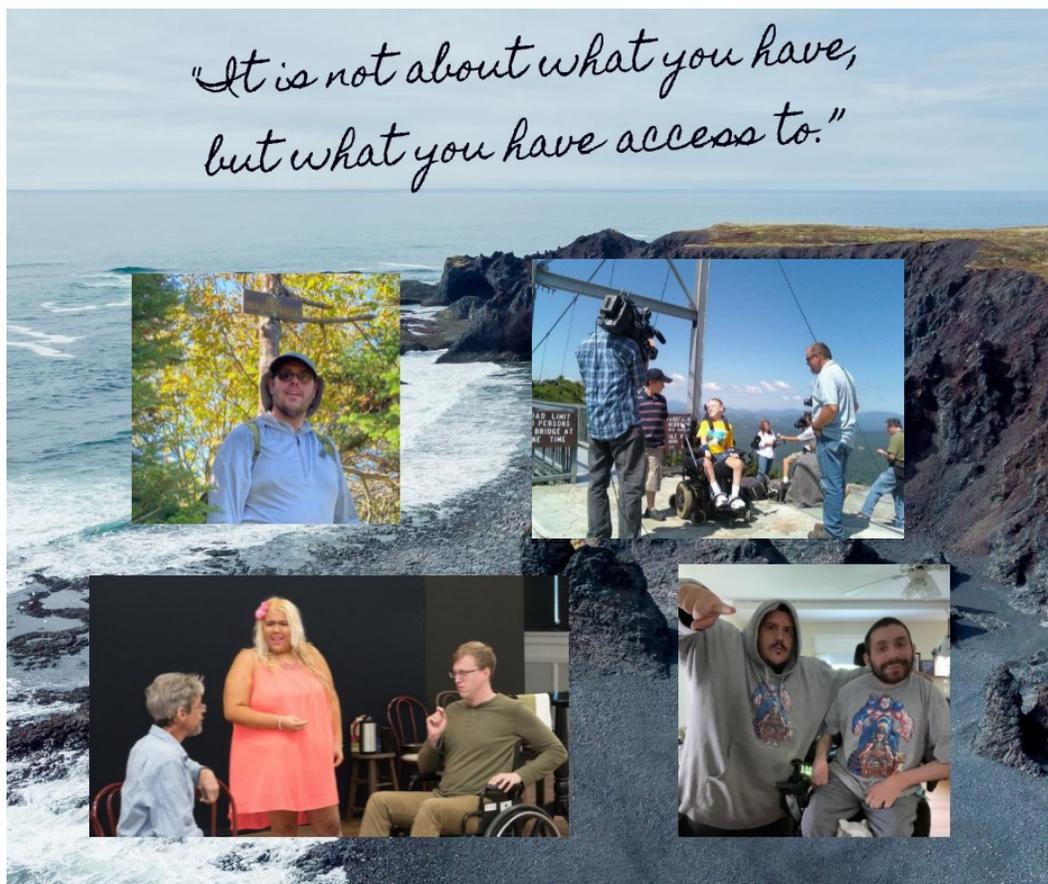


Also, let us know if we can help you start your professional journey!

Check out ALL the services available at Dee's Desktop Publishing

DeesDesktop.com

The Binnacle's First Year Journey



Accessibility does not always mean being physically able to participate. It can also mean being able to access information and stories that we see ourselves in. The Binnacle has done that. With stories of other individuals with developmental disabilities written by themselves and their families, our readers have relatable content that encourages and informs.

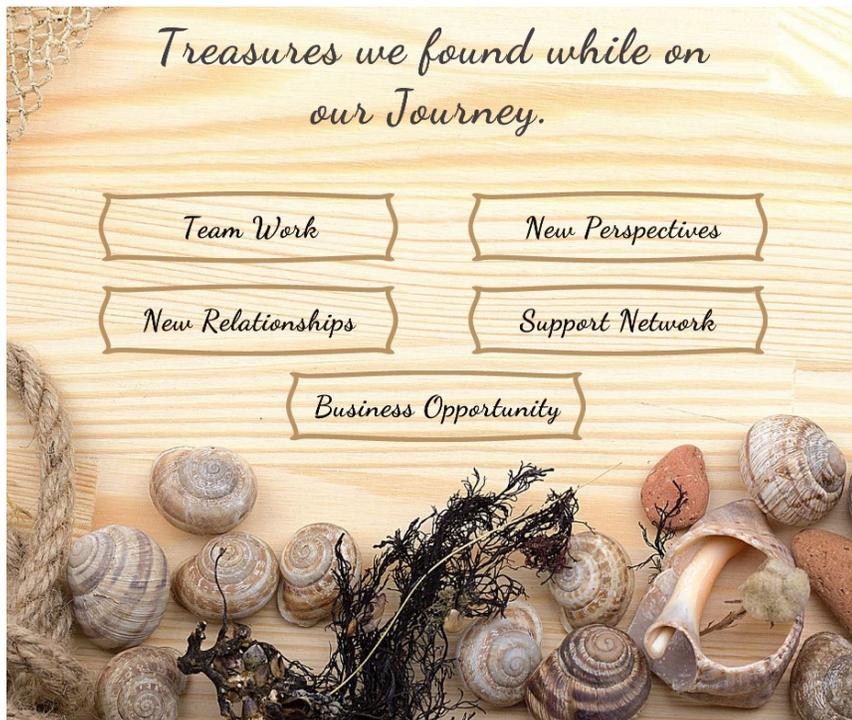
During our first year of preparation and discovery we took a good look at our personal lives and came up with a foundation built on three very different journeys. Then we reached out to others in our circles to add their stories who also reached out and we now have stories of those that we are meeting for the first time. We are truly becoming that Compass that shows us the way to new relationships, expanded advocacy, and a sense of belonging.



Although The Binnacle is a short publication compared to others, the topics that we cover are bold and powerful. Topics that individuals with I/DD really care about and involve personal experiences. By presenting the information in this way, it can inspire the reader to feel more confident in their situation. We also hope that readers without disabilities are inspired to see people with disabilities in a positive light.

The first 2 issues of The Binnacle have seen 8 contributors in Issue Number 1 and 17 in Issue Number 2. Not only do we invite readers to submit stories of which we have used ALL submissions, but we reach out to friends and colleagues in the field of I/DD to share stories and strategies. We have published pieces from 12 self-advocates, 4 parents, 1 sibling, and 2 Direct Support Professional. As well as the partnership that we have with The Power of the Dream, Inc, partnerships are being developed by ongoing collaborations with the NC Empowerment Network, Phillip Woodward with Access North Carolina, and NC DSP advocacy partners. Outside North Carolina we have partnered with the Inclusive Theatre of Western New York. We are confident that this list will grow as we continue to reach out.

After our first year we also decided our publishing schedule for three full issues per year. These will be in January, May and September. We can also work one on one with anyone who has something to share but needs assistance with the writing.



Aldea LaParr



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.



Community Supports

As a parent with a developmental disability, so much went through my head about how I would be able to give my children the best life possible. I believe one of the best things that happened to me and my children was me reaching out to community supports knowing that I was no longer a self-advocate for me, but for our family. I wanted the best for my children even if it meant asking for help, which was something I did not do often. I was always too proud to ask for help and often fell on my face before doing so. My mother even told me that my life changed when my first child, Andy, was born. "You are not so selfish anymore," she said.

When Andy was 3, he was eligible for home based Head Start. Once a week someone would come into my home just for him. Or that's what I thought. Those once-a-week visits at home when the boys were 3-4 years old, and then 4 days a week at the centers when they were 4-5 years old went on for 6 years. All three of my children, Andy, Timmy, and Scott participated in Head Start. Those years were life-changing for our entire family. But the last 2 years were very special.

When it was time for my youngest son Scott to start his home visits, that is when Dawn Meyers came into my home, and it never was the same. We ended up forming a friendship that I cannot even explain. Whenever I think of milestones in my entire family's life, Dawn's there. I would often escape to her home to decompress and have girl time. She always sent me home with snacks for the boys and sometimes even full meals.



After the boys were grown Dawn and I became even closer. Here we are at her family reunion.

The following is Dawn's words...

Scott says that he is the reason we are friends. He forgets that I met you when Andy was home based with Pearl and had class days with me. He forgets that Timmy was in class when I was a special needs assistant in the classroom. I returned to home base I think the year he began home base. I remember my first visit with you and Scott. He would have nothing to do with me or anything I brought. What he did was run from room to room, climb on the furniture, and stare curiously at me. The philosophy of Head Start is: the parents are the child's first teacher. This I take to heart and firmly believe to be true. While I can come into the home for one hour and a half session, as parents you have him 24 hours. So our relationship had already been established but our bond formed when you began to trust me. You welcomed me in your home and slowly you began to see that I was not to judge you or your parenting skills, rather I was there to help you strengthen those skills anywhere I could. Helping you teach the basics to your child. With Scott we needed to go one step back and get him to talk. Scott was nonverbal when I entered the home but soon opened up. At my first visit I saw that Scott was an active child. I also observed that Scott didn't need to speak; he had brothers who spoke for him. Second visit, I asked if he wanted to play with me and his mom and away he ran. So I began throwing a ball in the air and bouncing it. I had him! Scott came closer and grabbed the ball. We were forever friends then.

We began slowly integrating speech into play and slowly his vocabulary grew. Not just because of me but because Aldea and Gary continued the concepts with him daily. My only fear by the end of thirty two visits was that the LaParr's wouldn't like me. I turned their quiet house and nonverbal child around. When I left, they had a child that wouldn't stop talking. Sorry- not sorry. I'm happy I could help them teach their child and make a difference. It takes a village to raise a child and no one should ever feel like they are alone when there are so many resources out there available for the asking.



Dawn used her magic with children to get the boys to pose for this photo in 2000.



Person-Centered Planning

By Aldea LaParr

Person-centered planning (PCP) is a set of approaches designed to assist an individual to plan their life and supports. It is most often used for life planning with people with learning and developmental disabilities, though recently it has been advocated as a method of planning personalized support with many other sections of society who find themselves disempowered by traditional methods of service delivery. This includes children, people with physical disabilities, people with mental health issues and older people.

Wikipedia

This activity was designed to assist individuals and families in planning for their future and building their CIRCLES of support.

When I attended an Inclusion Institute for four days in 2009, I became fascinated in the MAPPING process that I learned. In our first issue of The Binnacle we showed a picture of Cassie's map but unfortunately, we did not explain what it was and why it is so important to many.



For more detailed information about Person Centered Planning: Paths, Maps, and Circles of Support visit <https://inclusion.com/path-maps-and-person-centered-planning/>

We did an activity together as a group one afternoon during the four days that was so much fun while teaching ourselves what was important to us as individuals. We were each given a poster size piece of paper and several old magazines.

We were instructed to go through magazines and cut out pictures, words, colors, and whatever we wanted to include in a collage about ourselves. Before long some of the group was spread out on the floor and we were having so much fun. It felt like a fun day in kindergarten for me and nobody held back.

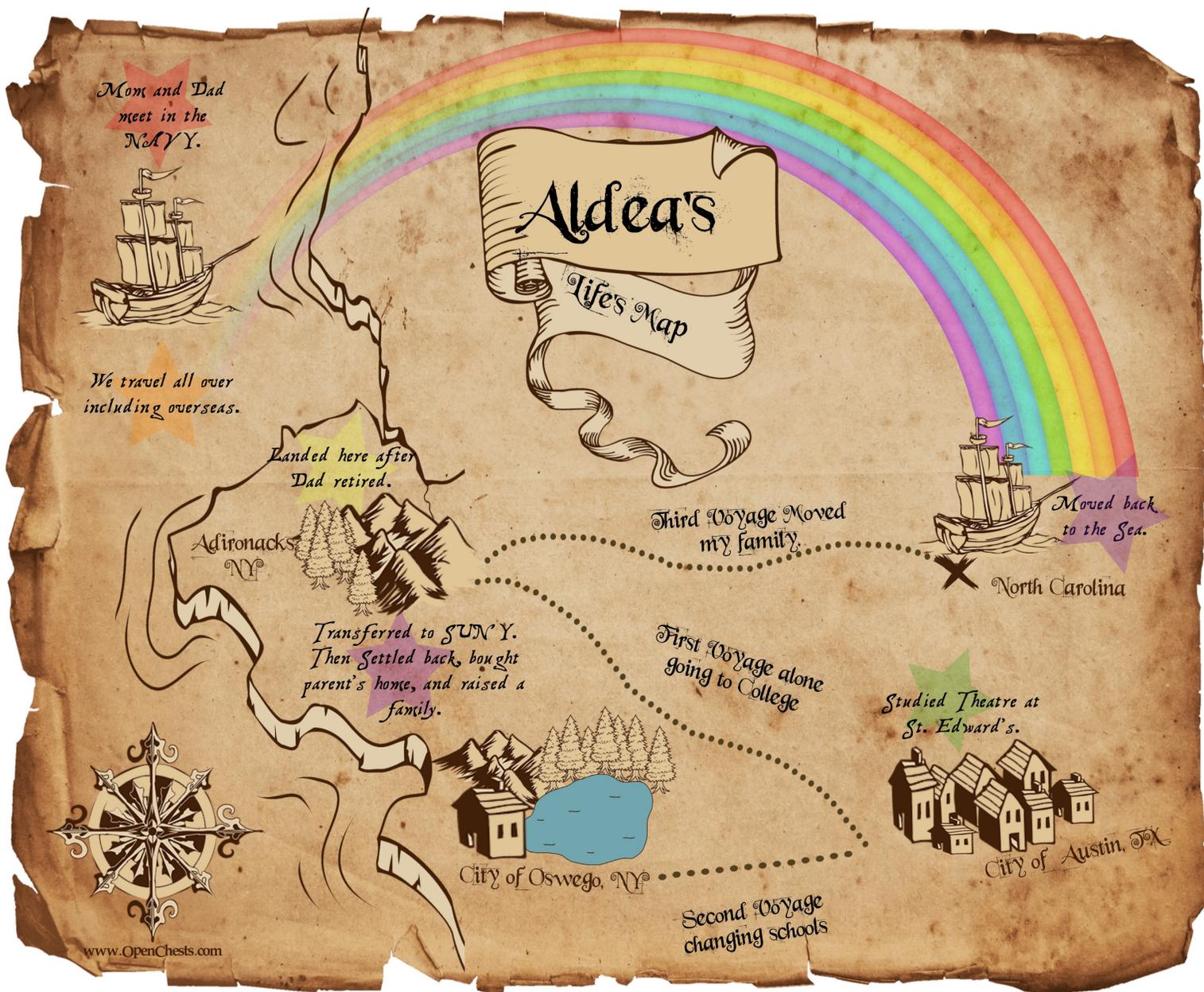


Another activity at the Inclusion Institute was kayaking. I had never been in a kayak in my life! But with coaxing by my friends, it happened! Of course I was in a two man kayak, but it was a huge step for me both physically and emotionally. I left that 4 day gathering with an excitement that I had not had before. I left with an empowerment and a new circle of friends who I can and have called on to this day.



I have learn so much during those four days about the power of a vision and how we all can benefit from dreaming about our futures and being aware of today.

As The Binnacle is purposely a magazine that highlights our journeys with a nautical theme, I took the opportunity to create my treasure map showing my journey. I encourage ANYONE with or without a disability to take some time to explore what would be included in your map.



We would love to hear from You!

We are looking for personal stories as well as exciting opportunities to encourage all who read The Binnacle.



We are very interested in what you think!

[Click Here!](#)

People with Disabilities Challenge Perceptions Daily

By Philip Woodward

North Carolina Council on Developmental Disabilities (NCCDD) Systems Change Manager

October marked National Disability Employment Awareness Month (NDEAM), an occasion that the U.S. Office of Disability Employment Policy (ODEP) celebrates through hosting events and sending posters featuring people with disabilities in the workplace to agencies and organizations who request these materials. But we don't want to set aside only October to celebrate the skills and talents that people with disabilities bring to the workplace. People with disabilities challenge perceptions and contribute in the workplace and in the community every single day.

Back in 1987, actress Marlee Matlin won the Oscar for Best Actress for her role in the 1986 film "Children of a Lesser God." Her win was groundbreaking – she became the first Deaf actor or actress to win an Oscar. No Deaf actor or actress had previously won – was it because they did not have the same opportunities that non-Deaf actors have? What else could Deaf people do to challenge this perception that perhaps Deaf people cannot act or play a leading role in a film? Fast forward to 2016 when Deaf model Nyle DiMarco won the Mirror Ball trophy on "Dancing with the Stars." If you ever thought a Deaf person might have trouble dancing in rhythm to music, did you know that Nyle's twin brother Nico, who is also Deaf, is a well-known D.J.?

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

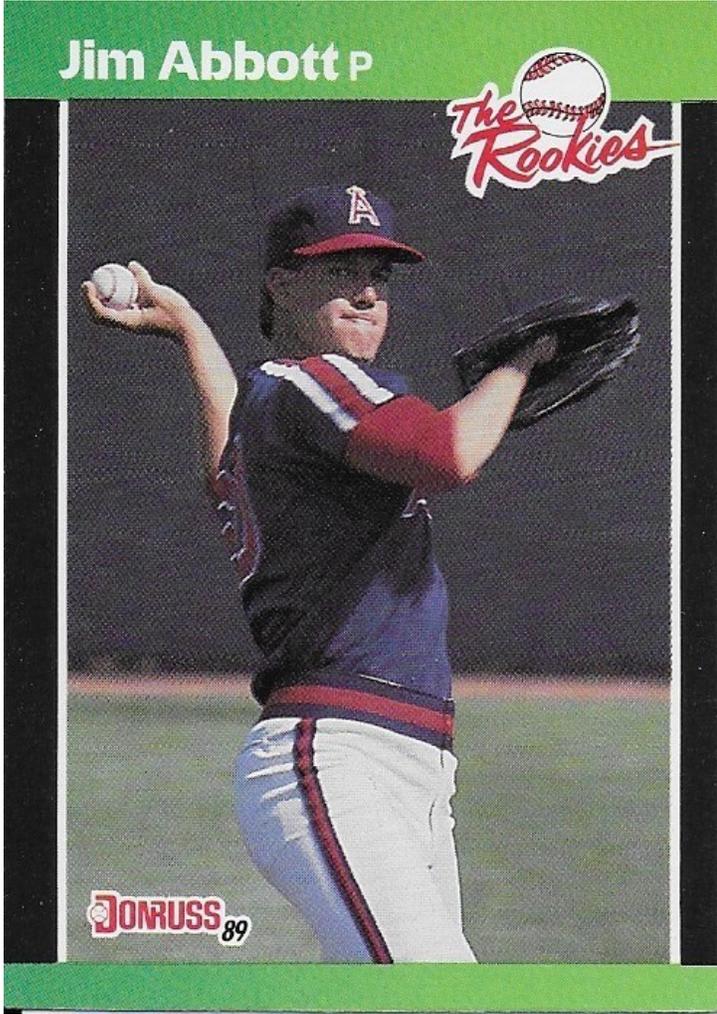
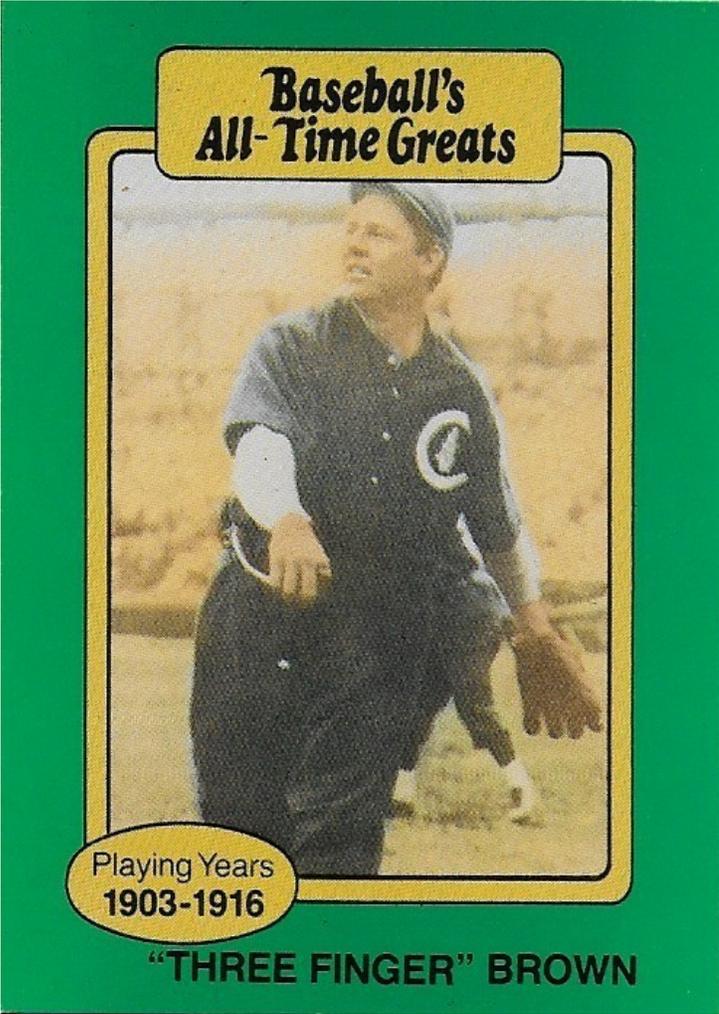


facebook



Another person who challenged perceptions on the baseball diamond was Mordecai “Three Finger” Brown, whose right hand was injured during a childhood farming accident. His injury prevented him from being able to throw a fastball, but his unique grip helped him throw an exceptional curveball that baffled batters, enabling him to win 20 or more games six times and to lead the Cubs to two World Series victories in the early 1990s.

Fast forward to the 1980s and 1990s, where one-handed pitcher Jim Abbott helped the USA baseball team win a gold medal at the Olympics, made the All-Star Game pitching for the California Angels, and threw a no-hitter for the New York Yankees. He was known for throwing a pitch and then slipping his glove onto his pitching hand to prepare himself to catch the ball. Mordecai and Jim turned their disabilities into superpowers to help them pitch successfully.



People with Disabilities Challenge Perceptions Daily continued

Likewise, people with intellectual and other developmental disabilities (I/DD) challenge perceptions on a daily basis. North Carolina Council on Developmental Disabilities (NCCDD) member Bryan Dooley has played many advocacy roles since graduating Summa Cum Laude from Guilford College, including serving as the Chair of the board of Disability Rights North Carolina and as a Vice Chair for NCCDD. But this year he landed a job as a Community Inclusion Specialist at Solutions for Independence, a Center for Independent Living located in Winston-Salem. Bryan can communicate effectively and participate in meetings and events with the support of his Direct Support Professionals and his communication device. He does not let cerebral palsy stop him.





Meanwhile, my friend Stacy Marx is breaking barriers of her own. She is not letting her Deafness, her cerebral palsy, or her spinal cord injury stop her from creating artwork. Her business, Stacy Marx Fine Arts, is taking orders from her friends to create pieces that feature fingerspelling names with background colors. Her dream is to display her artwork in a gallery one day. With a world-wide shipping crisis possibly limiting stores' inventories this holiday season, Stacy offers people the opportunity to purchase a gift of the heart and the hand.

If you are a person with a disability, think about what you are doing to challenge perceptions and contribute to your workplace and your community. Even if you don't realize your impact, the whole world benefits when everyone else does.



Nessie Siler



By Nessie Siler

Let's say you went to pick up your mail today. You're minding your own business and doing your own thing. Maybe you were even expecting a package from your Auntie Mabel. Instead of that much anticipated ray of sunshine, you are greeted by an official- looking envelope from the Social Security Administration regarding your SSI payments.

So now what do you do?

First of all, don't panic. Take a deep breath and take the letter home. The wording of the letter can sound intimidating and scary. These letters tend to use dark print and larger than needed font size. Try not to let that bother you.

Open the letter and read it carefully, or have someone you trust read the letter to you. The letter will explain why the Social Security Administration may be contacting you and what they need from you.



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.



After you read the letter, you may want to contact someone who is familiar with your case in the Social Security Administration to help you sort out how best to get the issue resolved. This could be someone in your local Social Security Administration office, or someone familiar with you and your case through your local Department of Social Services office. When I was dealing with the SSA, I used to contact someone in my local office first; they were able to help me sort things out a great majority of the time.



The North Carolina Empowerment Network

The North Carolina Empowerment Network is a new self-advocacy organization in North Carolina. We have come together to fill a void in our state regarding self-advocacy by and with people with disabilities in our state. Members of the North Carolina Empowerment Network work together to advocate, educate, inform and effect change for the better for people with disabilities in North Carolina.

Any person with a disability who is 18 years of age or older may join the NCEN as a voting member. The process for membership includes filling out an application and paying membership dues of \$5.00 per year. Family members may join as well, but as non- voting members.

To become involved in our exciting period of growth, please contact for further information:

NCEN Acting Chair: Cheryl Powell

Email: NCENemail@gmail.com

Facebook: [Facebook.com/NCENetwork](https://www.facebook.com/NCENetwork)

Voicemail Number: (919) 473-9110



Chris Wylie

Love Accepts

I'm Chris Wylie. I live in Western New York. I'm a 53 year old husband and father with disabilities. I'm a Methodist pastor. I have Cerebral Palsy.



Just before the pandemic, I met a musician by the name of Sam Baker. He's got a song called "Broken Fingers." He was on a train in Machu Picchu and the train got blown up. So he can't move his fingers so much. So I go to see him before the pandemic. The show was under promoted, so he had time to talk between sets.

Sam Baker and I were talking when I first met him, and I detailed to him the differences with my hands that can make creating music in a more conventional way difficult. He suggested I use Garage Band because I could drag and drop the notes in and the software would play.

Soon after this, I met MC Lars and expressed my appreciation for his talents as a freestyle rapper. I didn't think I could do that. He said, "Sure you could. Just use Scripture. Write what you know."

So in the beginning of the pandemic I joined his Lit Hop Academy and wrote songs. 14 of those songs were chosen for the album that I'm about to put out: Rolling Nation. It has both rap songs and conventional singing. One song is a cappella.

Presales have already started. One of the things that I want to do with the proceeds from this album is to start something to offer micro grants for adaptive vehicle modifications.

The thing I would like people to gain from the album is to expand your circle of love. Universal love is the force that brings us all together.



Chris Wylie lives in western New York. He married and a father with disabilities. He is also a Methodist pastor.



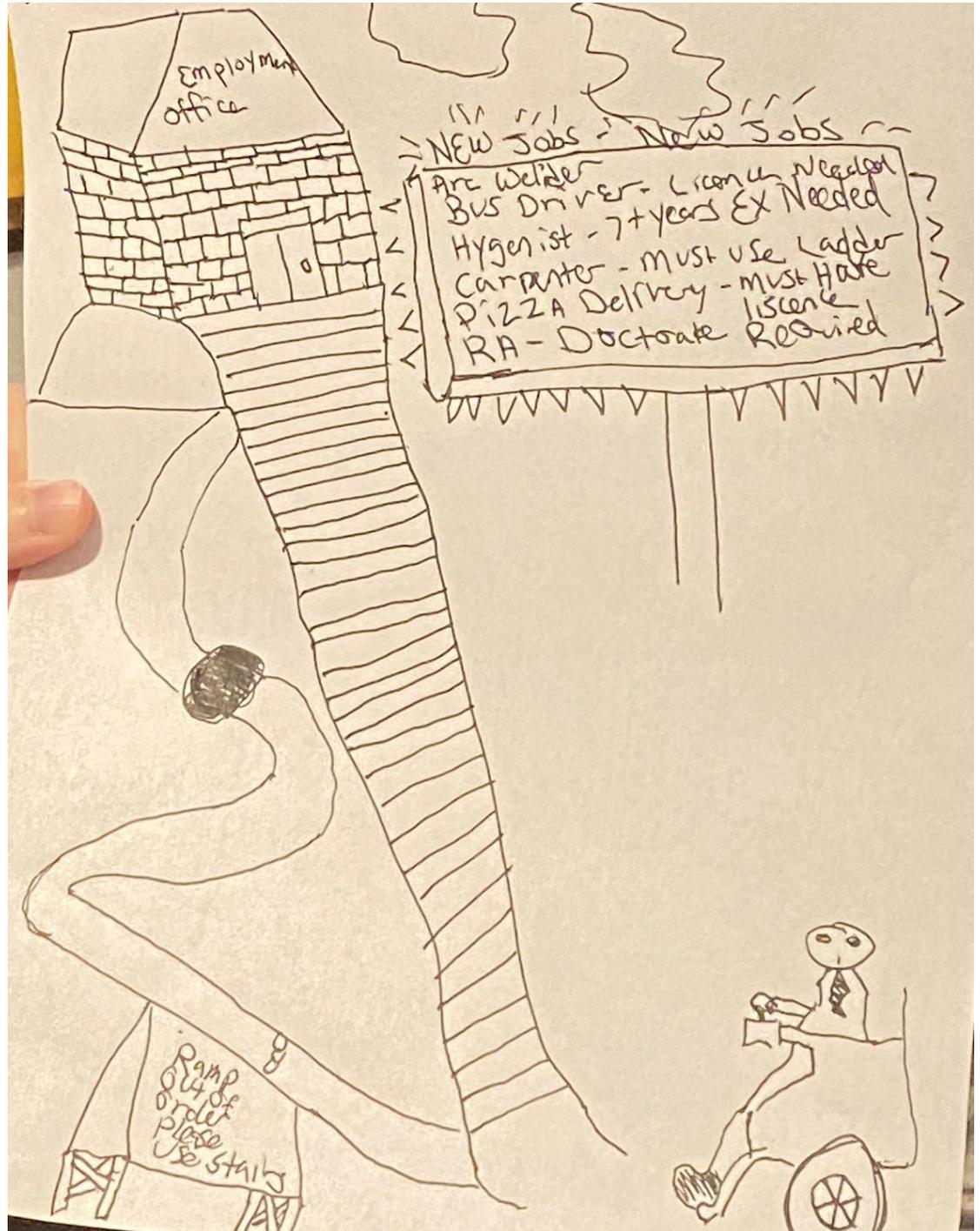
Love Accepts is a fund established to help people get wheelchair and other vehicle adaptations.

Visit <https://loveaccepts.com/>



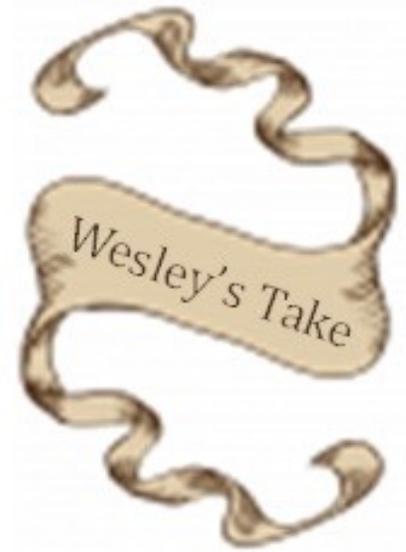


Meanwhile after a bachelor's degree and eight years experience...



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





An Interview with Wesley

Q: How and when did you get started in comics?

A: I attended what I think was the 8th birthday party of my friend, Brian. His mom had hired an actor dressed as Spiderman. This was in 1983. When I was 16, I started writing my own comics. But at the time I was unaware of industry format, so I was doing four or five page stories of my own stuff.

Our character here is a departure for me, because I'm used to drawing animals. But our editors said they wanted people, so.

Q: Does the wheelchair guy have a name?

A: Not yet. We're in search of a good name for him. I call him Will S. Chair.

Q: What would you like this comic to achieve?

A: I think we need to have more inclusive characters. I love the sense of humor that I can bring to all the things about our lives that nobody really talks about.





Wendy's Poem

YESTERDAY ALL WE COULD DO WAS HOPE

TODAY IS ABOUT TAKING ACTION

TODAY'S DREAMS ARE TOMORROW'S BELIEFS

BECAUSE WE CAN TRY

WE ACT UPON WHAT WE EXPERIENCE

DON'T BE PARALYZED BY FEAR

FOR IN THE END IT WILL BECOME CLEAR

REMEMBER ONLY YOU CAN MAKE IT HAPPEN

IN ORDER TO ACCEPT LIFE,

YOU HAVE TO APPRECIATE IT.

ONCE YOU HAVE GREATLY APPRECIATED IT

THEN YOU CAN ACCEPT IT.

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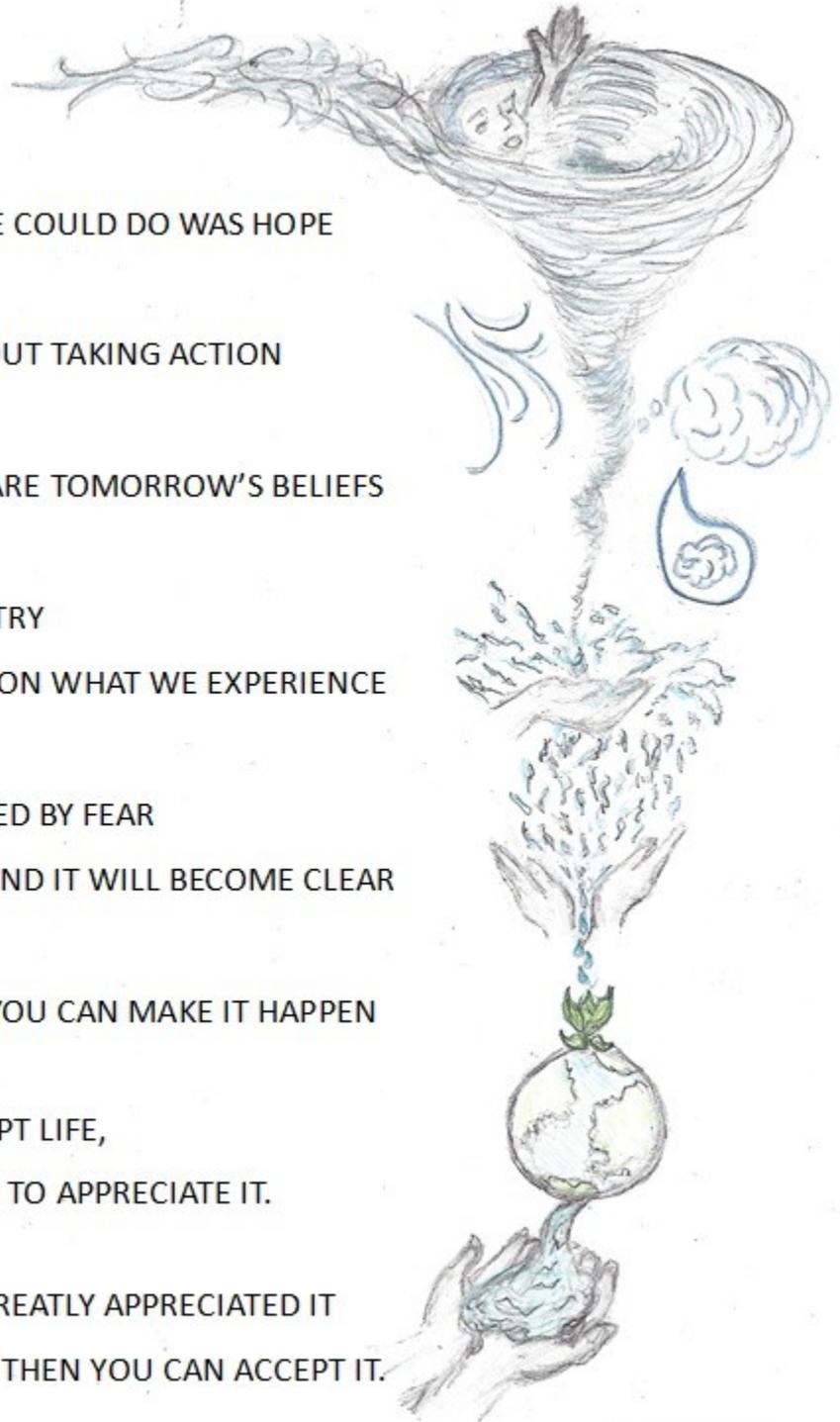


Illustration by CM

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. 



Resources Highlights



SARTAC

Self Advocacy and Beyond

The mission of Self Advocacy Resource and Technical Assistance Center (SARTAC) is to strengthen the self-advocacy movement by supporting self advocacy organizations to grow in diversity and leadership.



[Current Issues in the Lives of People with Intellectual and Developmental Disabilities](#)

What Resources would
you like us to share?

Let us know here!



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



For many adults with intellectual and/or developmental disabilities (IDD), a trained and engaged Direct Support Professional (DSP) means freedom. A good DSP will help adults with IDD enjoy being able to more independently meet their daily goals, get out in their communities and make their own everyday choices. This is called “living life” not just managing life. An individualized “medically necessary services” plan is agreed upon and the DSP helps the person with I/DD throughout the day, including getting dressed and ready for the day, being able to complete needed tasks to work, volunteer, access shopping, visit friends and family, go to the gym, library, classes, and all the other opportunities. The person with IDD is enjoying the best of each day in the company of family, friends, and support staff.

Like Superman saved the day, so do many DSPs, as they support and encourage the people they work with everyday to have meaningful choices and be able to participate in the activities they want to do. DSPs provide person-centered “medically necessary services” as per the individual’s support plan. Provider companies offer appropriate training for the DSP to meet the basic qualifications of what the DSP will need to know to begin the in-person training with the individual they will be supporting. Then, the on-the-job training begins and can last for months, depending on the specific needs of each individual.

Sadly, many adults with I/DD living in the community do not have a DSP and many more have unfilled hours in their days that have led to increased loneliness and even complete social isolation. A TV is not a replacement for human interaction. Even before COVID hit, it was an increasingly difficult challenge to find and keep DSPs. Now, since COVID, it has evolved into the defining challenge of our day as we are now being faced with a severe shortage of DSPs.



In the coming issues, we are going to take a deeper look into some of the several major contributing factors to this crisis, the implications of crisis shortage, and the evolving solutions that are being developed across the country to try to address this growing challenge.

**If you have input, suggestions, stories to share on this topic, please contact
The NC DSP Workgroup by emailing
ncdspworkgroup@gmail.com**



Next issue preview of topic:
“Defining ‘A Defining Challenge’ “



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