

Winterer 2023  
Volume 3, Issue 3

# The Binnacle

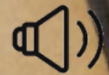
*Charting Your Own Course*



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** 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.



**Dee's Desktop Publishing** in collaboration with  
**Writer's Best Editing Services** and **Engage NC**

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**Comic**

**Wendy Orzel**  
**Poet/Writer**

Look for the telescopes for live links!



Interested in writing for us?

[VISIT OUR WEBSITE TO SUBMIT](#)

Submission dates are...

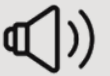
By March 15 for our Spring Issue

By July 15 for our Summer Issue

By November 15 for our Winter Issue



## Notes from the Publisher



One of the best things about our staff is the fact that we live this life every day. Over the last few months there's been frustration, questions, and tears in our own life that allows us to share real experiences with you all. But there have also been accomplishments and relationships that have encouraged us that we are better together.

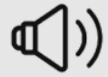
Via FaceBook, I was introduced to a friend of a friend who does professional voice over work. When I reached out about helping us, I found out he is also a parent of a son with disabilities. My heart soared! My goal here is to have The Binnacle be a tool for self-advocates and parents to share the struggles AND successes of navigating our lives. I am so excited to have Rob Raber join our team!!

We need more contributors! We need writers, artists, and resources that you think would fit with our mission. If you would like to write but want us to help you, please get in touch with us!

## Contact us!



# WELCOME OUR NEWEST CONTRIBUTOR!



We have real voice audio now!

Hi, my name is Rob Raber. I am a lifelong resident of Northeastern Ohio.

I am a proud father of four. My daughter Aniston is 15. I also have three sons Aiden 19, Owen 21 and Anthony 28. I have been married to my wife and best friend Stacey for thirty years this December.

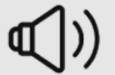
I enjoy fishing, farming I love reading and listening to books. Our oldest son Anthony was born with no hearing and no vision along with many other anomalies.

Being his caregiver has been extremely challenging but also very rewarding in ways we never imagined.



# 3 Ideas for Safe Ornaments

by Aldea LaParr



One thing that I learned through the years is the need for a safe Christmas tree. What do I mean? I love decorating the tree but having Cerebral Palsy that causes spasms made it hard for me to decorate my tree. I was always concerned about breaking something. Over the years and with the help of my children, I have built a great inventory of non-breakable ornaments.



## 1 Small Gift Toys

This is also fun! Both children and adults can turn the task of decorating into playtime.

## 2 Candy

There are so many types of Candy Canes these days! With all the many flavors now, there are so many colors!

## 3 Homemade Ornaments

Making your own ornaments can also be very unique gifts.

The picture shows my Christmas tree. Many of the toys that I have on my tree today are my favorite ornaments.



## Tangled thoughts

By Aldea LaParr



I believe that we have all been traumatized by something that has happened in our past. Lingering thoughts of those events and situations seem to get tangled up with positive thoughts that are meant to help us heal. Much of my trauma stems from my excessive need to fit in. What I believed was a healthy drive to be independent actually turned into an unhealthy obsession. I was so focused on what others thought that I was never content with who I was. I have had wonderful experiences that I am so thankful for, but no road map. My father actually often called me an unguided missile.

Then when I became a parent it got worse. Now I am responsible for someone other than myself. As a parent with a developmental disability, I was constantly thinking that others were thinking that I was an unfit parent because of my disability. I then had 2 more children. I am actually not sure how this thought became so intense because I had a great support system with friends and family, but I can not remember a time before this when I seemed to question everything that I did.

At the end of 1999, my husband and I were struggling with some major setbacks due to very poor choices. I was so eaten up by thoughts of failure and I saw no way out. Then my mom said something to me that was so simple but yet life saving for me. “Just do the next thing.” I was confused at first. She said just do the next thing that you need to do. It could be that the dishes need to be done, helping the boys, laundry, etc. Do not think too far into the future. That did not make sense to me because I totally believed that my choices got me into the messes and I was solely responsible to get me out of those messes.

Well, I started to do what she had told me. To this day my coping mechanism is housework because there is always something to do. She was right. When I concentrated on the things needing done that I could do, help came in time for things that I could not do. When my thoughts start to get tangled and I start to get anxious about a situation, I need to refocus. By physically doing a task makes it possible to refocus faster.

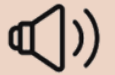
For me, this time of the year is very hard for me. With the holidays there are so many things that I want to do for family, friends, and myself that I can not. This is the time that I need to try to untangle those thoughts of “not enough” with “exactly what I need for today”. This can apply to finances, patience, knowledge, and time. Tomorrow may turn out better than you expect.

My coping strategy may not work for everyone. If you or someone that you are struggling with mental health issues, please consider getting help.



# Christmas Wish

©2023 Wendy P. Orzel



*T*he Holidays are here. Believe in your wish, whatever that may be As you're putting up your Christmas tree, decorations, and candles too. Create a home filled with holiday cheer, surrounded by those you hold dear.

*W*e gather around with family and friends. Having a glass of eggnog or hot chocolate too

*R*emember those who maybe in need, our friends in service and those overseas. We share and remember their sacrifices too.

*W*ishes are not just for Christmas but all year through. Here is our Christmas wish from us to you. If you wish to tell an old tradition or two or maybe start with something new.

*T*he Christmas wish will be up to you.





# A BASKET OF GIFTS

by Philip Woodward



The holidays are coming up. Thanksgiving. Hanukkah. Christmas. Kwanzaa. New Year's Day. And more.

The holidays are a time when people give and receive gifts. But gifts do not have to come in wrapping paper. Gifts do not need to be a toy that you play with for 30 minutes and then set aside. There are many other types of gifts.

During the North Carolina Council on Developmental Disabilities' Natural Support Network Development initiative, the Asset Based Community Development Institute (ABCD Institute) taught us about three types of gifts that everyone can contribute to their communities: gifts of the head, the heart, and the hands. What exactly are these gifts? Here is a description of each:

1. Gifts of the head: things we know about or pay attention to
2. Gifts of the heart: things we care about or feel passion for
3. Gifts of the hands: things that we like to do, make, or create

Can you think of an example of someone who has each type of gift? I sure can!

My friend Gavin has a gift of the head because he knows so many interesting facts about the singer Freddie Mercury and his band, Queen, and has taught me so much about them.

My friend Bryan has a gift of the heart because he cares deeply about the Direct Support Professional (DSP) crisis facing North Carolina and devotes a lot of his time to discussing this issue and sharing his story to help everyone understand the importance of paying DSPs well and elevating the profession as a whole.

Meanwhile, my friend Aldea has a gift of the hands. She can take a collection of stories, articles, pictures, and poems and compile them all into a newsletter called The Binnacle. Have you ever read it before??

What are your gifts? Think about what you can offer to your family and your community. Has anyone ever told you that you are exceptionally good at doing something such as building puzzles, telling jokes, raking leaves, baking pies, throwing a football, singing Christmas carols, or something else? And what gifts do you see in other people around you: your family members, your friends, your colleagues, and other people whom you spend time with?

During this holiday season, as you gather with other people, consider creating a basket of gifts. I am not talking about a big basket that you put together and raffle off for someone to win a movie night at home or a fine dining restaurant package. I am not talking about a basket filled with wrapped toys. I am talking about a basket with little pieces of paper or notecards where everyone you gather together with writes down a gift that they have on a piece of paper or a notecard. Then, instead of having a bunch of wrapping paper to recycle later, you all will have a newfound knowledge of each other and ways that each of you can contribute to a stronger community. Isn't this what our world needs right now?



Gift for You

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Gift for You

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Gift for You

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Gift for You

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# Gift for from Nessie




Approximation of Mom's Gingerbread and Lemon Sauce  
Thanks to [justapinch.com](http://justapinch.com)

Prep time 15 minutes  
Cook time 45 minutes



For Gingerbread

Ingredients:



1 cup light brown sugar

1 cup green label molasses

3 cups flour

1 and a half cups black coffee

1 heaping teaspoon of baking soda dissolved in the black coffee



A half cup of shortening or butter, softened

Half a teaspoon of ground cloves

1 teaspoon of cinnamon

1 teaspoon ginger

A quarter teaspoon of nutmeg




To make the gingerbread:

1. Prepare a square baking pan. Spray with cooking spray and flour the pan.

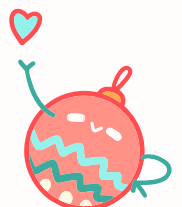
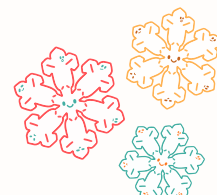

2. Mix sugar, shortening (or butter) and molasses together.

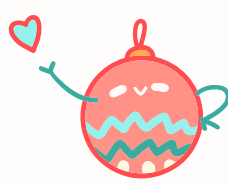
3. In a separate bowl, mix flour and spices together.



4. Then mix all together and blend in the black coffee which has the baking soda in it.

5. Pour batter into the prepared baking pan, bake in oven at 350 degrees for about 45 minutes.



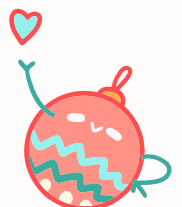
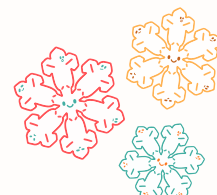
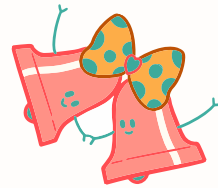
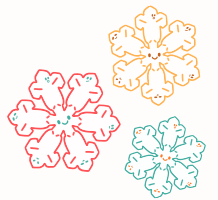


## Lemon Sauce for Gingerbread Naomi H. Pruden

### Ingredients:

- 1 cup sugar
- 2 tablespoons cornstarch
- 4 tablespoons lemon juice
- Pinch of salt
- 4 tablespoons butter
- 2 cups boiling water

Mix sugar and cornstarch. Add boiling water and a pinch of salt. Boil until thick and clear. Continue cooking over hot water for 20 minutes. Beat in butter and lemon juice. Grated lemon rind may be added.





Encouraging messages of love and support to share.  
DO YOU HAVE A MESSAGE? Please share with us!





I quickly learned the service delivery system and the power of being a self-advocate. Without being aware of the title “Self-Advocate”, I was one. I had lived all my life striving to be as independent as possible by informing those around me what I needed to live independently.

Sometimes I have felt that the term Self Advocate was not being used properly. I have felt pressured as a self-advocate to be involved in highly charged demonstrations that made me very uncomfortable. I also have had someone ask me how much money I make as a self-advocate. I told her that being a self-advocate is not a paid position, but a lifestyle. She was confused. It’s a lifestyle because we are advocating for ourselves every day in some way. It may be at the grocery store asking for certain products to be available on a lower shelf, having some groceries double bagged for safety. Speaking up about anything allows us to live as independently as possible.

I also believe that we as self-advocates need to make sure we are comfortable in that role in our personal lives before participating in a group effort to effect change. Effective advocacy comes from lived experience and the heart. When we are confident that we can speak for ourselves then we can feel more confident to speak as a group or organization.

I believe that it is hard for some to fully understand self-advocacy. Often, we need to educate those around us as to the “why” before we can get to the “how”. That’s where I struggle sometimes. We are asking to be valued as individuals while solutions are being made for groups based on the individual’s diagnosis, location, and income.





# NCCDD Self-Advocate Discussion Series Article

By Chris Hendricks, Policy Education Coordinator, NCCDD



As Self-Advocates, we know that we exist within a broken system of support. Thanks for stating the obvious.

Now what?

Well, we must ask ourselves where change starts in the first place. Does it begin with action? Does it begin with confidence? Those are important features. The truth is, change begins with a sense of community, safety, desire to act, and being informed. That is all at the heart of the North Carolina DD Council's Self-Advocate Discussion Series.

For one hour in the afternoon every third Wednesday of the month self-advocates feel safe enough to listen, learn, share, and discuss topics that are important to us and our community. Recent topics have included housing, transportation, employment, the direct support professional crisis, personal/intimate relationships, leadership development, and gratitude.

Over the last year, participation, and more importantly, the confidence of our community has really been shining through. How do we know that? Our Self Advocates are not afraid of speaking up.

“The more we are known, the more chance we have of becoming a bigger part of the society we love,” says Nessie Siler.

“This series helps us find common ground with decision makers,” says Tamika Gibbs.

In addition, it’s wonderful to see other self-advocates recognizing their own power and the value we all bring to the table. Essence Scott said, “As a self-advocate, I bring innovative thinking and a pioneering spirit to any environment. This is one of many advantages self-advocates have in today’s world.”

These are just a few examples of our community in action. We are the very definition of nothing about us without us. As we continue to support each other in leadership and knowledge it is clear that the self-advocates in our discussion series community are poised to be heard and build a better world for people of all abilities one topic at a time.

The image is a YouTube video thumbnail for a discussion series. At the top left is the NCCDD logo. The main title is 'Self-Advocate Discussion Series' in a green and blue banner, with a red play button icon in the center. Below this, it says 'THANKFUL November 15<sup>th</sup>, 2023'. On the right side, there is a 'Share' button and a speech bubble that says 'I think that..'. At the bottom left, there is a 'Watch on YouTube' button with a play icon. The background features a map of North Carolina and silhouettes of people.



## MESSAGE IN THE BOTTLE

by Nessie Siler



### National Disabilities Employment Awareness Month

National Disabilities Employment Awareness Month (NDEAM) began in 1945 as National Employ the Physically Handicapped Week. So we've moved from a week to a month of observance. Yay!

I didn't know about either of these time periods honoring the entry of people with disabilities into the workforce until I was 35 years old. By then I was fortunate enough to have had several jobs. So I knew it was possible for people with disabilities to be employed, and was glad to see recognition of that fact. I was pursuing my degree in Disability Studies at Goddard College when I came across an NDEAM poster in a professor's office.

At that point, I was just glad to learn that such a month existed. The poster also validated for me that I wasn't alone in wanting more for myself and my life than I had been conditioned to believe I could have. Other people with disabilities had done likewise and succeeded in their achievements. I have, as the years have gone on, noticed that NDEAM seems to still be aspirational even 70 years later. I don't hear of people with disabilities getting employment all that often. This is I am sure, problematic for Vocational Rehabilitation offices across the country. I haven't even heard them saying much about it over the last 15 years.

So my question is this: How can we make it better? How can we better champion the cause of employment for people with disabilities? Competitive integrated employment is in its infancy. Microenterprise has helped some of us. Any other ideas are welcome!

The COVID pandemic has offered us one boon at least. It has shown us that companies can accept and encourage remote work when it suits them. It's amazing what you find out when you have to make accommodations for everyone, not just people with disabilities. And that for the most part, accommodations for workers with disabilities are not the excessive hardship companies have been moaning about for decades. Now, the idea of remote work isn't foreign to most companies, though there is a push to get back to in person office work. I think that's just because it's what most people are used to. One thing I am hoping is gone forever is the "requirement" to be able to lift and carry 50 pounds, even if you're supposed to be a receptionist and the heaviest thing you lift in that job is the receiver on a phone. And even that can be modified these days- thank you Bluetooth headsets!

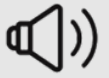
It is said when you know better, you do better. So I would say let's get to work.





## The Dignity of Risk

by Nessie Siler



My late mother- Naomi Heath Pruden - has been on my mind quite a bit lately. Mostly I've been wishing that I could have done things differently. My sister and I were born in the early 1970's with Cerebral Palsy. This was a time, I gather, when parents of kids with disabilities listened even more closely than they do now to whatever "experts" they could find to help them navigate the challenges of a child with a disability. My parents went where most parents were told to go at the time- to the Shriners Hospital where they were told that they could leave us in good hands and go about their lives.

My uncompromising, loving, beautiful 23 year-old mother said, "No! Over my dead body."

"Dossey," - my dad - "pick her up. We're going home."

My father, being young but also wise, followed instructions and picked my sister up. We went home. And nothing was ever the same for them again. Over the years, they loved us, protected us and made sure we had everything we needed. And quite a few of the things we wanted. We were kids, and we were raised as much like other kids as we could possibly have been. Despite the struggle and the constant doctor's appointments, and the expense, and the looks from total strangers. And not knowing how anything was really going to turn out for any of us.

It is not now nor has it ever been easy to raise a child with a disability. And there are so many unknowns about each disability that can differ from child to child because each child is different. And I know from my conversations with parents of children with disabilities that they do the very best they can with what they have.

I know my parents did, too.

There was one thing that I never understood, though. As I grew up, it seemed to me that my mother was afraid to ever let me try anything. This issue became so acute that as I grew up, I would refrain from telling her about anything that I was even attempting because she would surely tell me why whatever it was I wanted to actually do wasn't a good idea.

She was scared. I knew it then and I know it now. I know she would have felt so much better if I had done things her way. But I was the difficult one, and her way wasn't going to fly with me. This meant that a lot of the things I did, I was doing without a safety net.

I also know - thanks to some excellent training in advocacy through Partners in Policymaking and the brilliant Al Condeluci - that there are two very important things every person must be allowed the opportunity of in some form, whether they have a disability or not. These are: the dignity of risk and chances to acquire social capital. Social capital seems like the small stuff. But it's not. It's huge. It's what you get when going out in the community, whether to a coffee shop and the barista sneaks some extra sugar in because she knows you'd never ask for it.

It's when the clerk of your local bookstore knows just what to recommend for you because you've come in every week for a year. It's when you go thrifting on Saturdays and they know you there. Your patterns have led to people that you know and who know you because you all like the same things and have built relationships around and with likeminded folks. Real relationships are crucial for us all, and even more so for people with disabilities. Getting out in the community means a chance to spend and receive the social capital we all use almost daily.

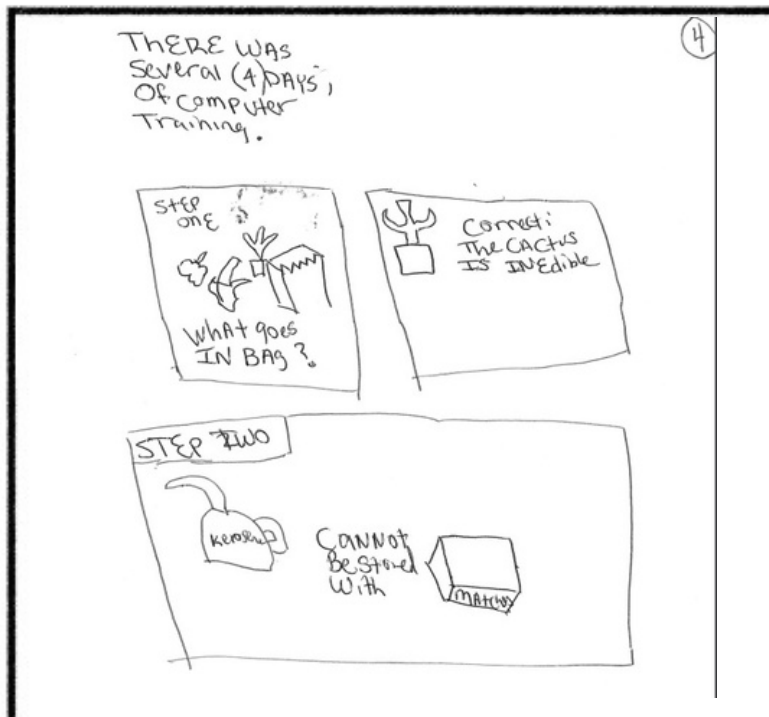
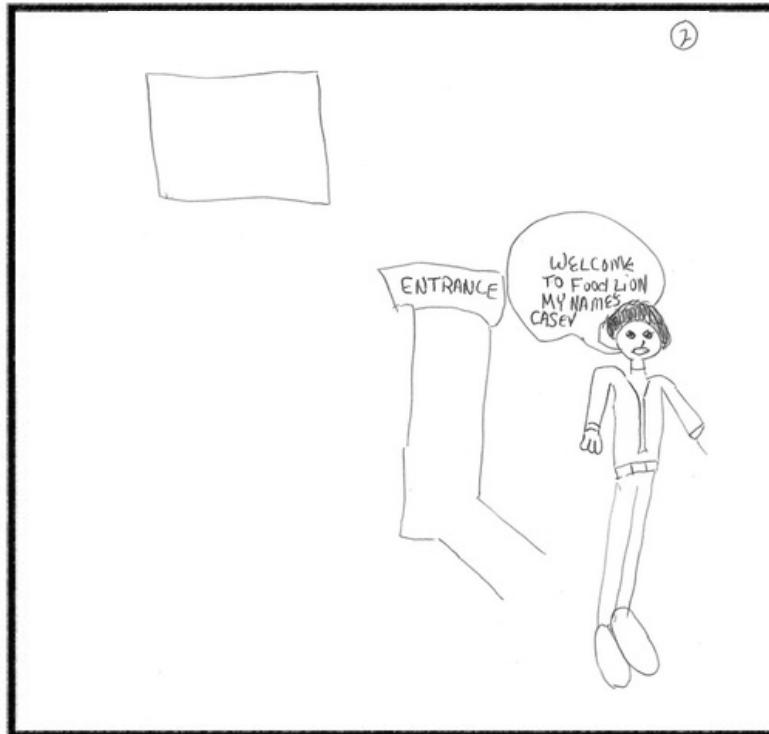
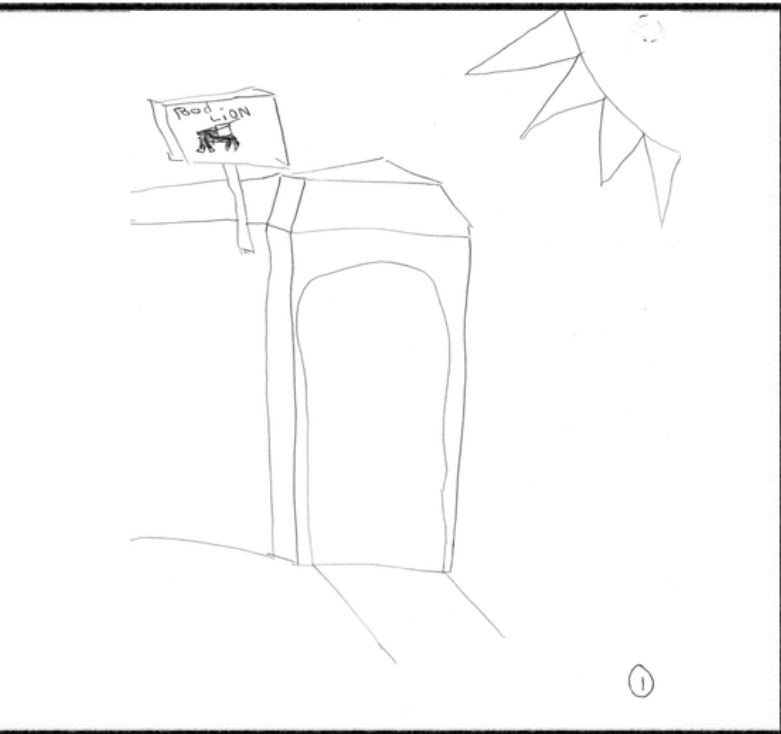
Getting to that point where you have social capital requires that all of us take risks. The risk of not know everything. The risk of trying something or someplace new. The risk to learn and to grow.

I implore you to have the courage to let your loved one with a disability try new things. Even if that new thing doesn't work out, it's still worthwhile as a learning experience. You never know where it might lead. And the more your loved one's social circle widens and the bigger you grow their circle of support within that social circle the better it can be for all concerned.

Including you.



# Wesley's Take



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After four days ....

I got into The real Training



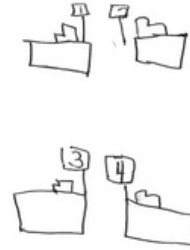
I LEARNED  
About SKU (Stock  
Keeping units / And

BARCODES  
0740341976

I ALSO GOT TO LEARN ABOUT



SELF  
CHECK  
OUT



A TOTAL OF  
7 Registers



7



I could vacillate  
Between The seven  
Registers and open  
UP BAGS ....



Switch out Receipt tape  
... ..

Help customers check out.



That's  
CARD only NO  
CASH!

8

And I've done it for 3 years ...  
OR 156 WEEKS ...  
OR 1096 Days (with days off, of  
course).

THE END (for now.)

To read more, see all  
8 frames in a .pdf

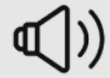
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To read more of  
Wesley's comics, go  
to our website at

[TheBinnacle.net](http://TheBinnacle.net)



# Our Favorites from



Have you ever found yourself at YouTube because you wanted to look up something specific only to find that you have been on the site for hours just fascinated by all the things you see? I have heard the term, YouTube rabbit hole and I find myself there daily.

One of my all time favorite videos is a dance to a song called **Jerusalem** by master kg. The song is in a different language than mine, but it is infectious. After seeing a video of children from Africa dancing to it, more and more videos of people all over the world dancing to it came up in my YouTube feed. This song has spared dance challenges from all over the world!

Here is the link to learn how it all got started.

<https://www.youtube.com/watch?v=gYhm6PCUtSg>

I was excited to find this video of individuals in wheelchairs dancing too!





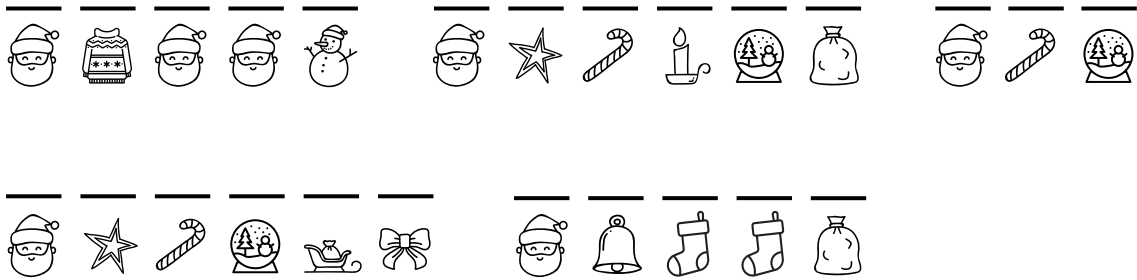
# CHRISTMAS TONGUE TWISTERS

## CODE BREAKER

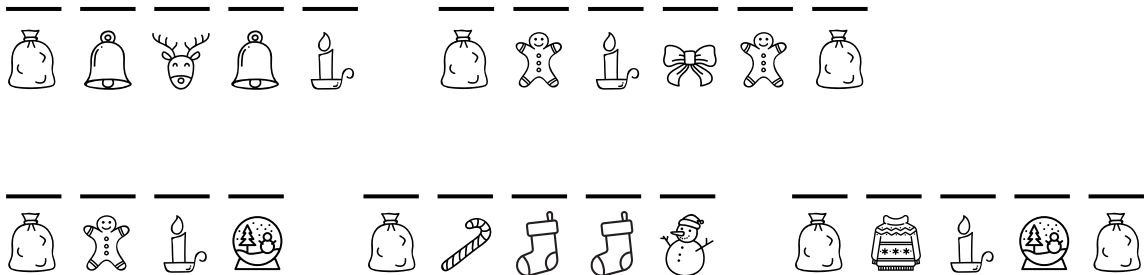
A	B	C	D	E	F	G	H	I	J	K	L	M
N	O	P	Q	R	S	T	U	V	W	X	Y	Z

Can you decode these Christmas tongue twisters? Use the key to break the code

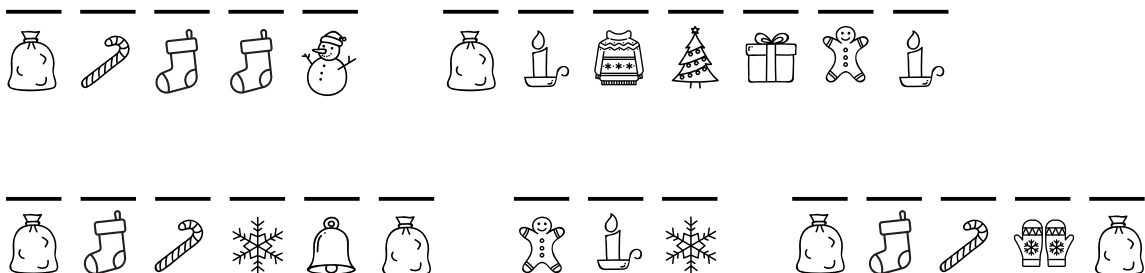
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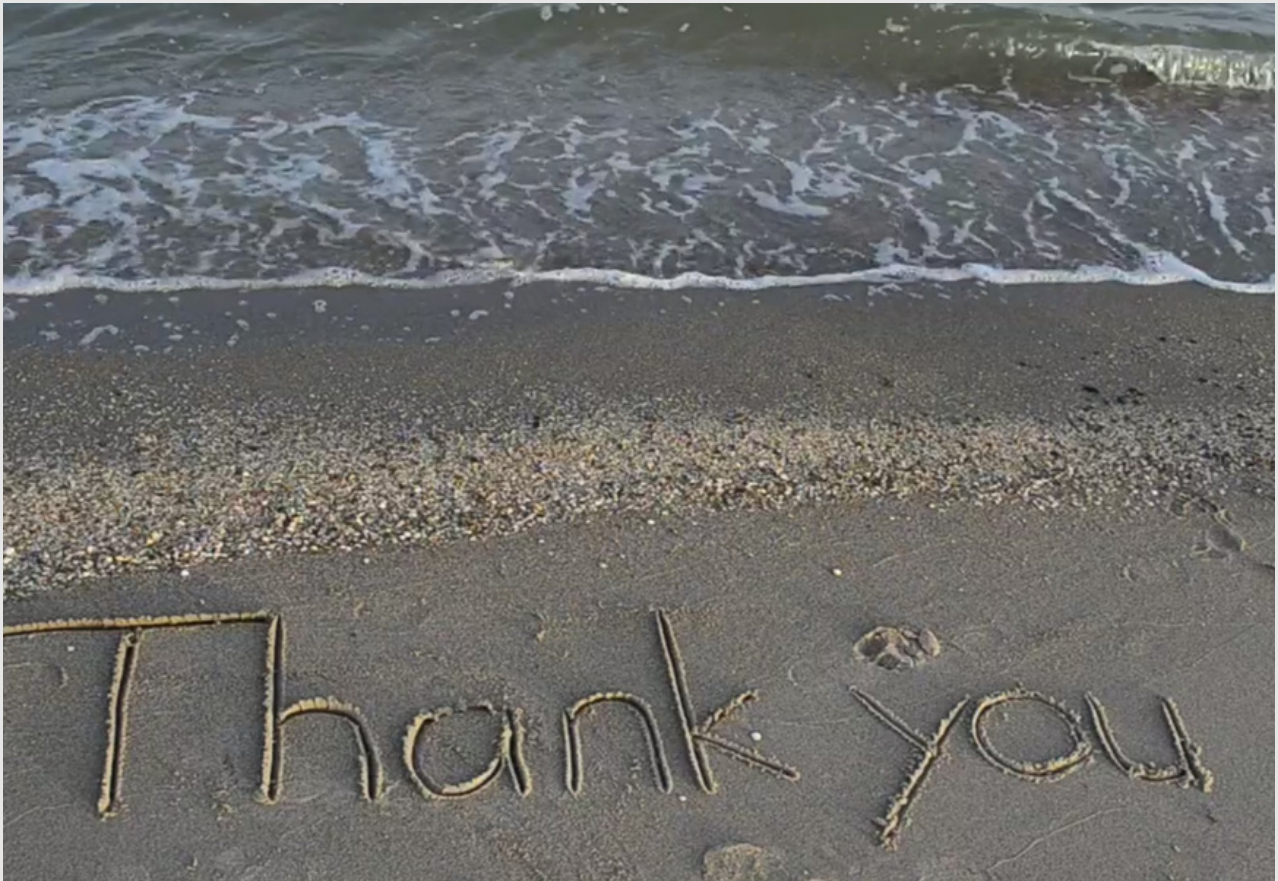


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