

Ability Diversity
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Marianne DiBlasi, Rebecca Kelley-Morgan, and Heather Janules

First Reflection

Ability Diversity

Marianne DiBlasi

The very first time I walked through the doors of Winchester Unitarian Society was in 2010. A former member, Sally Patton, was leading a workshop on Welcoming Children with Special Needs. Sally is a mom whose son was diagnosed as severely dyslexic as the age of five. I remember her telling us, this launched her on a spiritual journey of discovery and healing. It was also the catalyst for Sally to deepen her advocacy for how to welcome ALL children into a congregation.

The nugget of wisdom I recall most vividly is Sally's perspective on labeling a child as disabled or any other identity – *"Labels are for cans and jars, not for people."* To label a human being as Disabled, Black or Brown, Trans, Non-binary, Queer, Muslim, Elder or Child puts the focus on one aspect of their identity instead of focusing on the whole person. For anyone who has been labeled in a way that has caused harm, how often have you wanted to scream *"This is not who I am. My label does not define me. Won't someone please see me for who I am? I am so much more."*

When I was born, medical professionals gave me the disability label of Spina Bifida, a partial paralysis from the waist down. The doctors told my parents scary stories of how difficult their newborn child's life would be. My parents heart ached for the bleak prophecy of their child's future. But they did something quite remarkable: they defied the doctors' prognosis and said, *"Nope, not my daughter. She won't be limited by the label of disability. We will treat her normal, just like all our other kids."*

My parents' pivotal choice of how to raise me like my siblings meant:

- I went to the neighborhood public school.
- I took swimming lessons.
- And, my father taught me how to ride a bike. I learned how to ride a bike.

Which I think back on now and realize how extraordinary that was. My parents decided to teach their daughter who has balance issues and walks with crutches how to ride a bike – because they treated me "normal" just like all their other kids. And, I'm grateful they did. I LOVED riding a bike. I loved flyin' like the wind! Free and fast!

I had these experiences because my parents didn't believe in the limiting label of what medical professionals said I could and could not do. Instead, they chose to let me Be Me. Together, we learned what was possible. Maybe I could ride a bike, maybe I couldn't, but the only way to know was to try and see what happened.

Being treated normal just like all the other kids gave me many gifts, yet there was also a downside. I thought “normal” meant being able-bodied. I thought the only way to succeed in life was to be “like everyone else.”

So, I tried really hard to do everything the Able-Bodied way. I climbed hills, went sledding, took dance lessons, applied for a job as a waitress – yes, as a waitress who carries trays of food and drinks to customers – because that’s the kind of job my friends were applying for.

Over the years, this quest to be “like everyone else” took its toll. I was exhausted from the huge effort of trying to achieve the impossible – to live life the Able-Bodied way. I forgot how to be fully me, which included the truth of having a body with some physical limitations. I was on an impossible mythical quest because, in truth, there is no such thing as “normal.”

The author of, *The Lightning Thief*, was written by a father whose son lived with the learning differences ADHD and dyslexia. Coincidentally, the story’s main character, Percy Jackson, is a teenager with ADHD and dyslexia who struggles in school and is on a quest of trying to understand why he’s different than everyone else.¹ He tells his mom, “*I can’t focus. I stink at school. My ADHD gets the best of me. Dyslexia not cool.*” His mom tries to reassure her son that he’s destined for great things. She tells him: “*One day, you’ll see that what makes you different is also what makes you strong.*”²

Soon after, Percy discovers he’s a demi-god; son of the Greek god Poseidon and his human mother. He discovers the learning differences he struggles with are actually part of a demi-god’s superpowers, which he uses on a perilous journey to find Zeus’ lightning bolt to prevent a war between the Greek gods.

Similar to Percy who is both a Greek god and human, I am both disabled and able-bodied. Both are true. A significant part of my spiritual journey has been to accept the differently abled parts of myself – knowing that abilities come in many flavors. There’s no “normal way” of moving in the world.

I’ve moved using crutches since I could walk, so I was comfortable using them. A wheelchair, on the other hand, was something I thought of as, “*the dreaded thing to be avoided at all costs.*” I did NOT want to use a wheelchair because I thought it would limit my mobility and label me as more disabled looking.

Then, I went to a Spina Bifida conference where people used all sorts of mobility devices: crutches, canes, walkers, scooters, wheelchairs. I noticed people who were using a wheelchair went zipping right past me, while I was struggling to walk with crutches down long hallways. I remember thinking, “*Hey, what’s wrong with this picture?!? I’m using so much energy to walk, while others are just zipping along!*”

¹ <http://rickriordan.com/2005/09/the-learning-disabled-hero/>

² <https://www.themusicallyrics.com/1/427-the-lightning-thief-the-musical-lyrics/5152-strong-lyrics.html>

In that moment, my view of the wheelchair shifted. Instead of slowing me down, a wheelchair would help me to go fast! Did I mention I like to go fast? I do! So, I quickly bought a little purple wheelchair!

The wheelchair hadn't changed one bit, but how I saw it changed dramatically. Instead of being limiting, using a wheelchair, gives me the physical freedom to fly like the wind, just like when I was riding a bike as a little girl. More significantly, I experienced spiritual and emotional freedom when I let go of the negative label I associated with a wheelchair. It's just a wheelchair. It's the meaning I give it that makes it limiting or freeing.

In truth, there is no such thing as a disability. There are just a diversity of different types of abilities.

- Some of us sing, play chimes or another musical instrument,
- And others use eyeglasses or listening devices to see or hear more clearly,
- Some of us cook, knit, build things, or do magic tricks
- While others walk up stairs, and some use a ramp, a stair lift or elevator

There are a million different ways to do things. If we don't label one as better or worse than another, then each way is an expression of our unique, diverse abilities – of talents and gifts that only You can offer. Since you can only be your unique self, Be You! Be You to the best of your ability. Because the world needs you just as you are – with all your marvelous diversity.

May it be so.

Second Reflection

Different AND Creative

Rebecca Kelley-Morgan

In a spell of dry weather, when the birds could find very little to drink, a thirsty crow found a pitcher with a little water in it. But the pitcher was high and had a narrow neck, and no matter how they tried, the crow could not reach the water. It was so frustrating to have water so near and so unreachable.

Then an idea came to the crow. Picking up some small pebbles, they dropped them into the pitcher one by one. With each pebble the water rose a little higher until, at last, it was near enough so they could drink.

And that my friends is what scientists call “adaptation” because that’s what beings, including human beings do. If it doesn’t work for us, we change things, we invent things, we create and we adapt. And also, science is cool

Now we aren’t crows and we generally don’t find pitchers of water in our sanctuary here, but we do find “adaptation”. It’s us at our most creative.

- In this room some of us stay in one place, and some of us move around when we all say “hello” at the beginning of the service
- In this room some of us wait for a candle to come to us, some of us wait to light a candle over here
- In this room some of us use microphones and headsets when we talk because we cannot talk that loudly so that people hear us.
- And in this room, there are people who use timers and reminders and bells so that they don’t have too little attention, or too much
- In this room people like me - use really big font so they can read in this lighting. Other people use tablets because you can change the lighting or enlarge the writing to see it. Also, technology is science and science is cool!
- In this room lots of people pick their spot in the pews for a reason - ones where they can easily get in or out, or ones where they can see everything that’s going on, or ones where they can easily leave the room if they need to.
- And in this room people might be using devices to help them hear better. My sister wears these little tiny things to hear better - also science – and science is cool!

There are lots of ways that we change it up to make the world – our homes, our schools, our workplaces, our hobbies – work better for us. We create and we adapt. And because we are all different, what works for me might not work for you. But that’s what makes the world so interesting, so full of diversity. And diversity is something we celebrate, because do any of us REALLY want to live in a world where everyone is exactly the same?

And if our differences have encouraged some of us to form new understandings, to create and invent new gadgets and technologies, to find brand new ways to do things or change up the old ways to fit us better - we are all better off. Also, science is cool!

Third Reflection *From Ramps to Relationships*

Marianne DiBlasi and
The Rev. Heather Janules

Marianne:

As an intern minister, I’m learning how to be a minister to the very best of my ability. I’m learning the many ways a minister serves a congregation, while also learning how to be my unique expression of ministerial presence.

- A lot of ministerial development is visible to the congregation – preaching, leading worship elements, rites of passage, attending meetings and the many events at WUS.
- There are also parts of ministerial development which happen behind the scenes, such as weekly supervision sessions with Heather.

A theme that has come up often during our weekly meeting is the both/and of – what is the role of a minister AND how do I do ministry my way, which includes being a person who has physical mobility limitations.

- In Heather's role as intern supervisor, I rely on her to offer me an authentic experience of life as a minister.
- As a person who has physical mobility limitations, Heather relies on me to know what I can and cannot do.
- Figuring this out has been challenging because – I've never been a minister and Heather has never lived my way of moving in the world.

We're both learning from and with each other. Within a container of mutual trust and respect, we both speak authentically from our own perspective AND listen with the intention of understanding the other. As conversation partners, Heather and I are curious, open-hearted, and willing to see the world through the eyes of the other. This way of communicating allows us to collaborate and come up with creative, adaptive ways of doing authentic ministry that honors how my body moves.

It's not perfect. We continue to experiment, figure out what works and what doesn't. But, we do it together and we learn from each other.

Heather:

Here is how I would tell the story. I remember the day I called Marianne to ask her to become our student minister. I was so hoping she would say yes! To my delight, she did.

But we had to make sure the building accommodated her mobility needs before the "yes" was official. So, one day we went on what called "the accessibility tour" with Chuck Khuen from the building committee. We learned we would only need to modify the steps to the pulpit to make this work and, because Chuck can work magic with wood, this would be an easy fix. So the yes was official. Such wonderful news!

But that wouldn't be the only change. I realized that my usual way of walking in with the worship associate and John the music director at the beginning of worship might be a hardship for Marianne, so I modified our approach. If one minister struggled with a part of our liturgy, the liturgy would change for all the ministers.

And, early on, I realized there was value in Marianne and I being in the space together before a service and thinking through how we transitioned from one moment to another. If you have been coming here for awhile, you know sometimes we have rituals with flowers or water or flash paper and sometimes our worship associates dress up like elephants or wood sprites and dance around. There are often a lot of moving parts to manage!

These meetings before services were helpful. In time I got a sense of how things should be organized so Marianne could move in a way that was safe and comfortable without a negative impact on the worship experience.

But then we discovered a challenge. Most Sundays, we have two worship services, Family Worship at 10 downstairs in the chapel and this service at 1030. A minister has to be here in the

sanctuary at 1020 to meet the chalice lighters. So, leaving Family Worship and coming to the sanctuary requires the elevator and two long walks if one does not use the stairs. This is hard to do in ten minutes and impossible to do by 10:20. Technically, one can get here by 10:30, but it asked a lot of Marianne. For awhile, before the stair lift was replaced, it meant she had to get in her car and drive around the block to come to the sanctuary.

I thank Marianne for telling me how stressful it was to make this journey. But I didn't know what to do. As she said, my job was to introduce her to the experience of ministry. As an able-bodied person, I know that working as a minister sometimes means going from one thing to another with no time to waste, carrying bowls of water or flowers or elephant masks. We found ways to make this less taxing. But, as she said, it hasn't been perfect.

I also want to thank Marianne for telling me what she needed at other times. There was one service where she was getting ready to light the chalice. I was sitting closer to the chalice and offered to switch seats so she would have a shorter journey. She thanked me but explained that the bench she sat on was higher, making it easier for her to stand. I never thought about the height of chairs as an accessibility issue before. I would not have known if she didn't tell me what she needed.

Marianne and I have been working together for almost two years. Like all student ministers, she has taught me so much about ministry. And, as a person with a disability, she has taught me a lot about ability diversity.

Some of these lessons are practical ones, like thinking about the height of chairs. But there are spiritual lessons too.

There are two primary lessons I have learned:

Maybe the world we live in is not organized in a way that really works. I mean maybe no one – including able bodied people like me - should have to run upstairs with wood sprite costumes or a basket of flash paper to make worship on-time. Instead of just asking Marianne to stretch to meet the needs of the role, there is also a need to ask what is most important in a role, about how to lead and serve in a way that is sustainable for everyone.

The second lesson is somewhat of a paradox. To be an ally to people with different needs and abilities, it is important to plan ahead, to have large print orders-of-service for those with low vision, listening devices to help people to hear more easily, and spaces cut out of some pews to accommodate people sitting in wheelchairs.

And by meeting people's needs, other needs might not be met. Like Rebecca, my eyes don't see as well as they used to so I like to have a bright light when I am reading. But I sometimes get bad headaches which become even worse if I am in bright light.

So, the only way someone would know what I need in a given moment is if they ask. That's why I called this reflection "From Ramps to Relationships." Having things in place to accommodate different needs is important, like modified steps into the pulpit. But what is most important is that we ask each other what we need, knowing the answer may change from time to time.

It takes courage to speak up, to say that you need something that is not offered by the community. And it takes courage to ask if there is a way we can be together differently that would allow someone to feel safer, more comfortable. More honored and recognized as who they truly are.

Speaking of being together differently, during the Community Greeting, you may have noticed; I come down to the Sanctuary level to say hello to congregants and Marianne doesn't. She chooses to remain on the chancel because it would take too much effort and time for her to go down the stairs and come back up.

This sacred space belongs to all of us. There is no wall between the pews and the chancel, so what's to stop someone from coming up to say hello to Marianne during the community greeting? Marianne, would you be okay with that? MD: Absolutely!

My hope is we can create and sustain a culture where the community tunes in to differences and responds creatively to those differences. I hope for that culture here in this sanctuary and beyond.

I pray for the courage to speak up for what I need and the courage to ask others. It is my prayer that we are, at all times, brave enough to honor who we are and brave enough to welcome each other's true self into community.