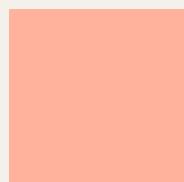
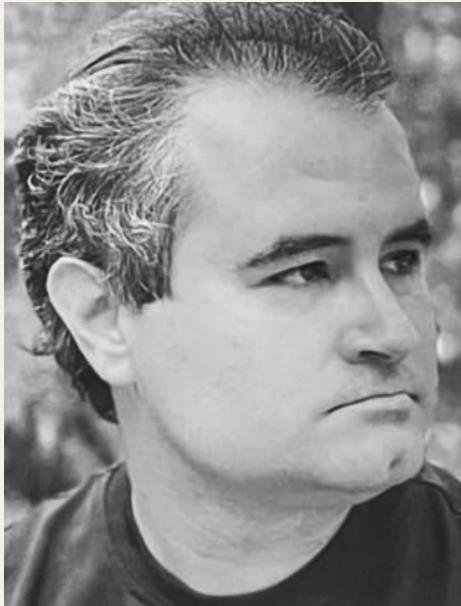


Lived Experience

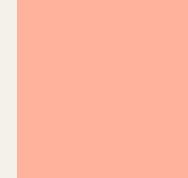
Kris Medina | GMSA
SARTAC | July 31, 2025



Hello!

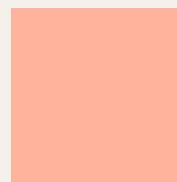
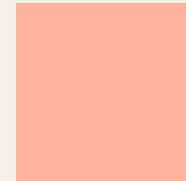


I'm Kristofor Medina.
I talk through typing.
I speak some words but
it's not all of what is
inside my mind.

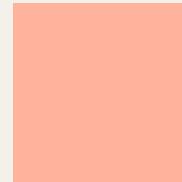


What is 'Lived Experience'?

If you haven't heard someone use the phrase '**lived experience**' before, it means our experience of having a disability and talking about how we live—from our work to our personal lives.



The opposite of lived experience would be someone who understands disabilities but is not themselves disabled.



Lived experience is entering each workplace with our whole selves.

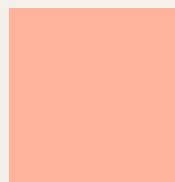


It is not the same as our self-advocacy movement.

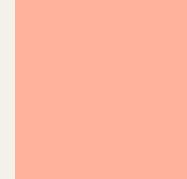


My Experience

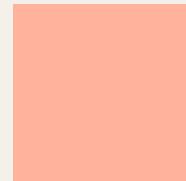
I am on the Vermont Communication Task Force. This is an advisory committee about people who use alternative communication like typing or sign language.



The group is mostly made up of people who work for agencies and the state.



We give recommendations to service providers and policy makers.



I feel like my lived experience as a typer with autism adds depth to our work.



My voice is respected because I understand how people who don't speak will be impacted by the policy work of the task force.



If we really want full inclusion in decision making then we need to embrace our disabled identity.



**The self advocacy movement needs
to be united to get our full rights.**

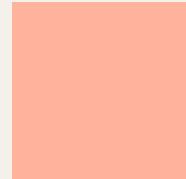
Why does 'Lived Experience' Matter?

I get wanting to pass and feel like someone without any problems.

We are not problems.

We are perfect.

The system that makes our lives challenging is the problem.



My Fight

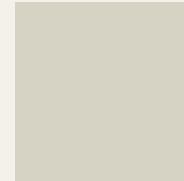
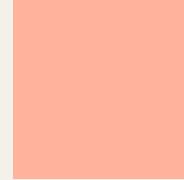
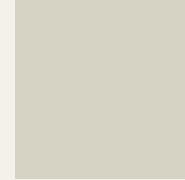
I think about when I was working really hard to get my degree and not everyone on the faculty believed I was intelligent.

I had to dig deep inside myself and tell myself that I was smart.

In May 2011, I graduated with honors from the University of Vermont with a Bachelors degree in English and a minor in Special Education

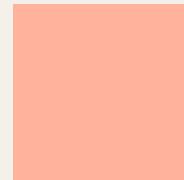
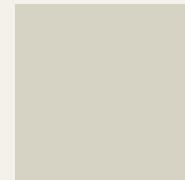


Love Yourself



The majority of people and institutions are ableist.

But we need to love ourselves fully to forge a new world where our disabilities are fully seen and celebrated!





Eric Matthes

Washington State
Community Advocacy Coordinator
for The Arc of King County

"Don't work on me but work with me"





One of our favorite quotes from
Lydia X. Z. Brown is:

“We will know that things are
really changing when the people
who have the most to lose are
the ones who are making the
decisions.”



Lived Experience as a Person with a Disability

First, know your disability. Know what works for you and what doesn't.

You know what helps you succeed being on a committees making decisions about our lives.

Who knows us better than we know ourselves?
We are the real experts here.





Step Two: Speak Your Truth

Step two is having the guts to speak your truth, even when you know it won't be popular.

Step Three: Handle Pushback

Step three is deciding what you're going to do when people tell you "no"—or worse, when they try to discredit you and say you're not smart enough to know what's best.



Tokenism on Committees

Often, we are just tokens on a committee.

They put us on to make themselves look good—to say they included people with lived experience.

But then they don't take us seriously.

They don't accommodate us so we can participate effectively. And often, the final decisions don't reflect our input or needs.

Showing Up with My Lived Experience



When I show up, my lived experience is being Autistic, Black, and living in a rural town. I have an intellectual disability. I'm adopted. I'm a leader in the self-advocacy movement.



Intersectionality

When someone has more than 1 identity. All of these things **intersect** to make up their unique identity.

My Identities, My Words

All of my identities make me who I am. All my different identities come with different labels.

I get to choose how I want to identify and what words I want to use to describe myself.

My Passion for Self-Advocacy

My job and my passion
revolve around the
self-advocacy movement.



Don't Take Away the Word 'Self-Advocate'

Now, some people are trying to get rid of the word self-advocate. We've heard it all before.

There are people both with and without disabilities trying to dictate what words I use to describe myself. It feels like they are trying to define me. Go ahead and do that for yourself—but not for me.



A Warning from Chester Finn

As Chester Finn told us the other day, “Some in the disability rights movement are trying to steal our identity.”

No Room for Identity Theft

In our struggle for disability justice, there is no room for identity theft!

It's fine if you want to go along with the new trend of calling yourself "a person with the lived experience of intellectual disability" and include all your other identities.

But beware of the "identity thieves" who try to tell us what to call ourselves.



Thanks!



Do you have any questions?



GMSAVT.org

