Harnessing the Power of Transparency, Vulnerability, and Lived Experiences to Enhance Health Equity Among Vulnerable Populations

Acknowledgements

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ARIZONA DEPARTMENT OF HEALTH SERVICES
Health and Wellness for All Arizonans

Southwest Interdisciplinary Research Center
Arizona State University

HEALTH EQUITY ACKNOWLEDGEMENT

Addresses Social Determinants of Health

Takes an Active Role in Community and Institution

Employs a Person-Centered Model of Care

Seeks to Avoid Bias and Provides Affirming Services

In our commitment to incorporating a health equity framework, DISH-AZ acknowledges the following:

- We recognize that social structures and institutions impact health outcomes– not just an individual's behaviors. Structural racism, unfair criminal justice practices, and other systems of oppression result in inequitable health outcomes at both individual and community levels.
- We all carry implicit biases that can impact how we interact with others. It is essential to recognize biases to avoid causing harm and provide affirming care to all patients.
- We will do our best to promote health equity in our programming, but we may not get everything right. DISH-AZ wants to hear from you how we can do better. When you complete the evaluation form, please let us know how we can make this and other presentations more inclusive.

Credit:

Partnerships

Southwest Interdisciplinary Research Center
Arizona State University

IN PARTNERSHIP WITH

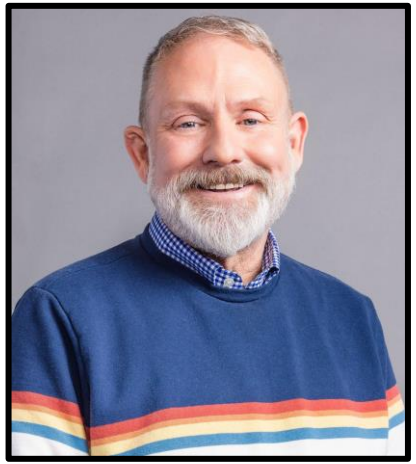
ARIZONA DEPARTMENT OF HEALTH SERVICES

ASU Southwest Interdisciplinary Research Center (SIRC)
OFFICE OF EVALUATION & PARTNER CONTRACTS

Works in partnership with local, city, county, state, national, non-profit, and governmental agencies, to perform evaluations and disseminate findings that support effective research-based interventions aimed at preventing, reducing and eliminating health disparities.

Today's Presenters

Members of the DISH-AZ Team



Rocko Cook
Academic Detailing Program Manager
Arizona State Univ/SIRC & Arizona Dept of Health Services
They/them

Dave Watt, CHW
Senior Educational Outreach Specialist
Arizona State Univ/SIRC & Arizona Dept of Health Services
He/they

Ryan Anderson
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Objectives

- Learn how our own cultures and personal experiences can be motivating forces to improve health equity, both for service provision and for provider education.
- Understand how our backgrounds, lived experiences, and anchors give insight to reaching and understanding the experiences of our clients.
- Participants will explore and develop their own stories that can be utilized to reach and understand their patients through an improved health equity lens.
- Examine how implicit biases and other pitfalls of our backgrounds and experiences can be barriers to service provision and health equity.

An Introduction to DISH-AZ

What is Academic Detailing?

Educational Method

A one-on-one or small group educational method where trained educators deliver evidence-based and tailored messages to encourage behavior change among providers or staff to improve patient health outcomes.

Unique & Adaptable

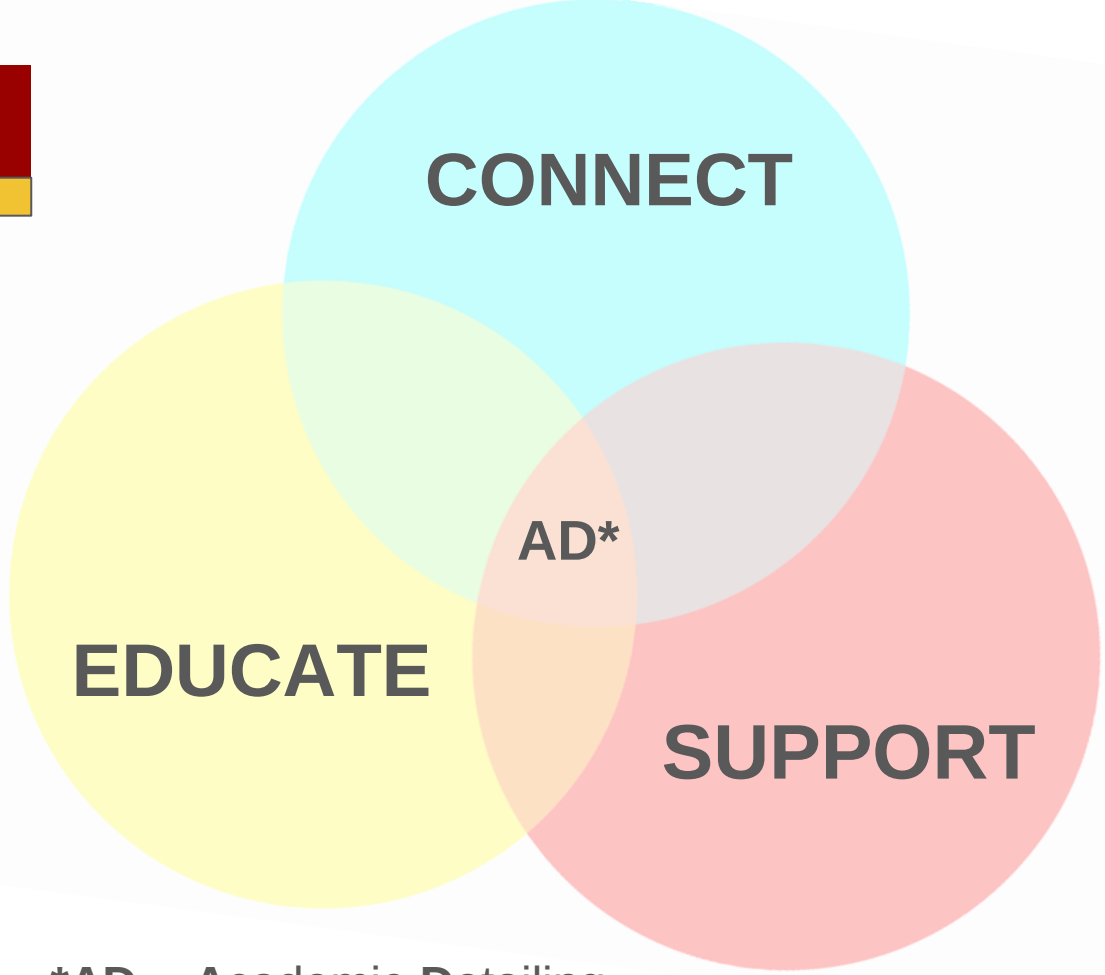
Each academic detailing visit is unique and requires adaptability on the part of the detailers; especially during the first meeting with a provider or staff.

Tailored to Clinicians

Detailers have a limited amount of time to provide a sense of structure, elicit a dialogue through needs assessment, active listening, and deliver key messages that are tailored to that provider’s/staff’s needs

WHAT is DISH-AZ?

Detailing for
Improved
Sexual (& Social)
Health in **AZ**



*AD = Academic Detailing

What makes DISH-AZ different?

- Partnerships
- **Backgrounds and experience**
- Approach focus vs. topic focused
- Flexibility in funding to ID gaps/needs
- AD as Workforce Development
- **Whole clinic care**

Best Practices for Whole Clinic Approach

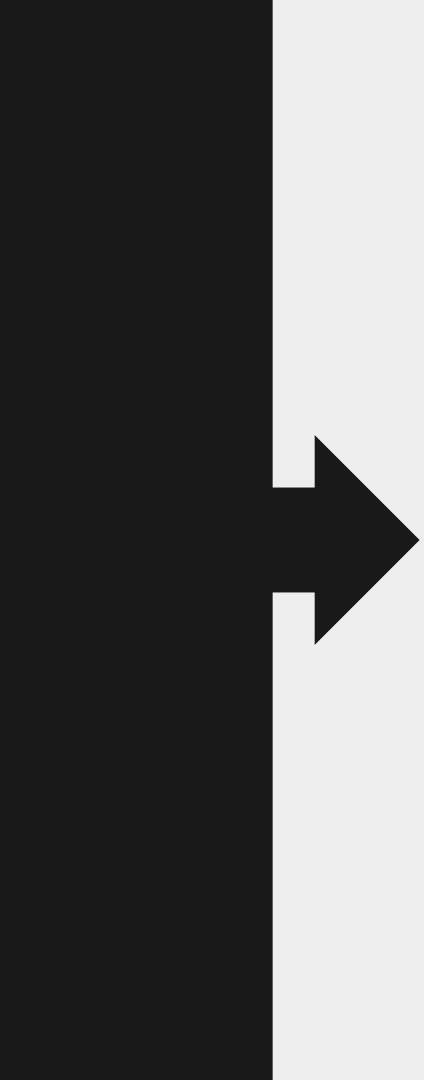
- **Identify professional and lived experiences of DISH-AZ team members.**
- **Encourage development of professional and expression of lived experience.**
- Start with connections already established with local agencies.

- Conduct a thorough introduction with the clinic and members of their team.
- **Show that your passion can meet with their passion *(what's your anchor?).***
- Meet them where they are and focus on relationship building as well as skills building. Goal is to meet on an ongoing basis…

CHAT WATERFALL

What are some ways that our patients/clients experience health inequities?

Of these responses, what are some ways that YOU have experienced health inequities?



Why tell stories?

Why do we share our stories?

Our stories can serve as anchors

- **When our jobs become difficult, taking a journey of self-discovery can help us identify our anchors, or the "why" of what we do for work.**
- **By processing our own history and experiences with health inequities, by learning to tell our stories we allow our lived experience to influence our "how" of what we do for work.**

According to a 2022 study published in the *International Journal of Pharmaceutical and Healthcare Marketing*, patient satisfaction can be greatly improved by relationship-oriented marketing powered by storytelling.

What is Storytelling?

Storytelling- A way to share our lived experiences. It bridges different worlds and helps us find a common understanding and improves the experience of providing/receiving healthcare.

Image credit:
https://www.growth-hackers.net/steps-build-storytelling-framework-resonates-target-audience/

Terminology and Definitions

Implicit biases- Often not self-realized, negative mental associations that can influence judgment and behavior. They are usually triggered by demographic characteristics such as race, gender, age, gender identity, and sexual orientation.

Unintended consequences- When the results of an action differ from the expected outcome (can be positive or negative).

Trauma- A distressing or disturbing experience sometimes associated with negative and repeated outcomes.

Boundaries- Parameters within which a relationship takes place. Helps ensure all parties' needs are met.

Rocko in Four Parts

1. Seminary to AVOL

In 1984, when I came out I left grad school and began working at AIDS Volunteers of Lexington in Central and Eastern Kentucky. Started the House of PRiSMS (queer youth group) in 2016.

2. Columbus Health Dept.

In 2000 I left Kentucky for Ohio to work for the Columbus Health Dept in HIV Prevention. In 2002, I was diagnosed with HIV and syphilis.

3. Left HIV work - drugs

Because of the weight of my diagnosis, I developed a lot of internalized guilt and shame, and experienced stigma. I began using injection drugs.

4. Returned to the Field

In 2008 I moved to Phoenix with my husband and my dog and found a community of support. I returned to the field of HIV in 2017 and am here today.

What’s your “why”?

Exploring Our “Why”

Why do we tell stories about our lived experiences?

- It makes our content more relatable and interesting.
- **Your stories are yours alone**, but others may need to hear them because they may reveal a truth or a motivation for them that could impact behavior change (transtheoretical stages of change model).

- It helps us to **connect** with our patients/clients on a deeper level, especially when there are shared experiences.
- **Shared experiences help us to connect** with and support our clients/patients.
- Moreover, we also **connect with ourselves** on a deeper level.

- Even when they are not shared experiences with our client/patient, **our stories can be more motivating** than pure data or information alone.
- By **becoming comfortable** with our own stories, we might be able to encourage our clients/patients to become comfortable with theirs.

Activity

Take 2 minutes to write down or share with someone else

Identify 3 of your “whys” or anchors for what drives you?

- **What motivates you to keep going?**

- **How might revealing your “whys” and anchors to others impact how you live your life?**

Ryan’s Story - Learning to Read in the Dark

- **Ages 4-23**: Began grappling with gender identity/sexual orientation
  - **Sleepless nights** trying to figure all of this out
  - **No queer role models**
  - Transgender identities were **never a topic of conversation** at home, in school, or in popular media
  - **Didn’t have the terminology** to describe the feelings
  - Once the teenage years hit so did the real difficulties
- **Age 24**: Began the process of socially and medically transitioning!
  - **Very few in-person role models** to turn to (thank goodness for YouTube!)
  - **Confusing and convoluted process** to navigate the medical transition aspect
  - **Navigating being denied health care** outside of gender affirming care
- **Present**: **I get to turn the lights on for other people navigating the transition process!**

Harnessing the POWER of Lived Experiences

How might our background, lived experiences, and anchors give insight to health equity?

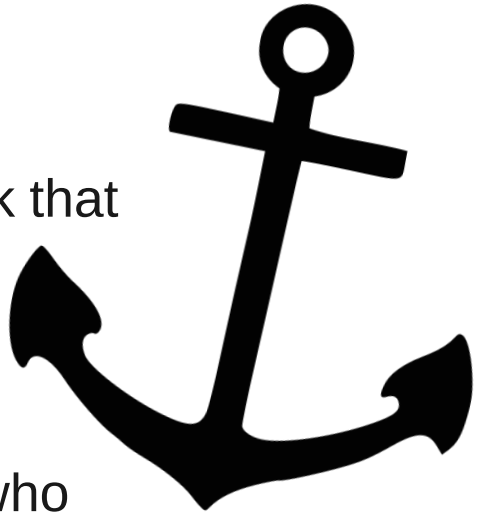
- We cannot divest the topics of Social Determinants of Health, sexuality, or substance use from the discussion of sexual and social health.

How do we know what creates successful programs that meet people where they are?

- Through lived experience, we can be informed regarding what needs a particular group of people might need in order to access and find acceptable service programs.

Activity

What's your "why"?



- Identify a few of your "whys" - why do you do the work that you do? Opportunity, skills, passion!
  - How did you get started in your field?
  - Who are your heroes?
  - Was there a moment in your life that influenced who you are today?

Tips:

- It does not need to overly complicated!
- What motivates you?
- Write it down.

Transparency, Appropriateness, and Boundaries

Transparency:

- Why is transparency important? Even if a lived experience is not shared, it is important that we not diminish the need for transparency. **We can live our authentic and full lives** and not self-disclose every detail.

- **Not every situation is the same,** and deciding the level of transparency we are comfortable with beforehand may alleviate some of our own stress in re-telling the story.

Appropriateness:

- Not all cultural, personal or lived experiences are helpful or desired, in fact **many times they should not be mentioned** at all.

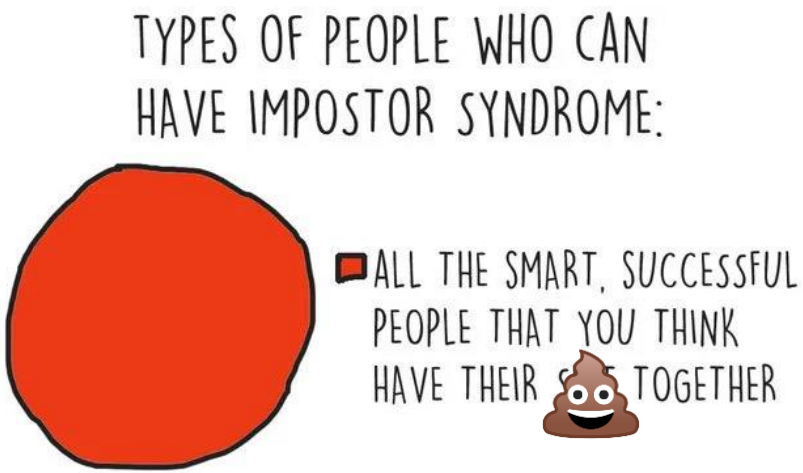
- For example, Rocko starting out as a PrEP Navigator, had to figure out how and when discussion of his own status should be discussed.

- More often than not, it was a boundary, but occasionally, it was appropriate and very helpful for the client.

Boundaries:

- **Deciding what we are comfortable revealing** and what would we would prefer to keep to ourselves is a VERY important part of storytelling.

- It is important to remember that, in the same way **we don't want to traumatize** our patients/clients, we don't want to re-traumatize ourselves by sharing something we aren't ready to share.



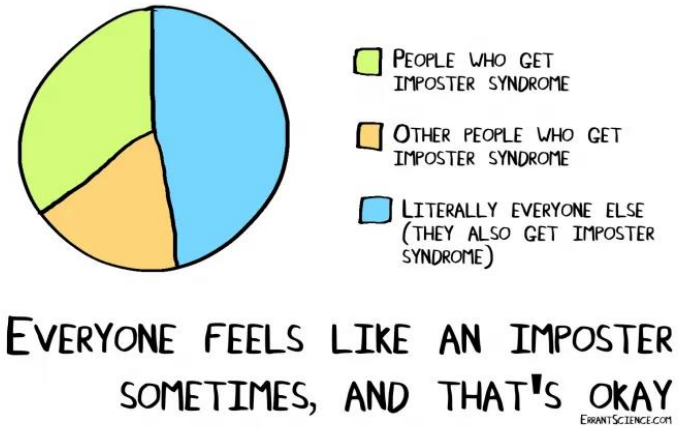
Imposter Syndrome and Pretending

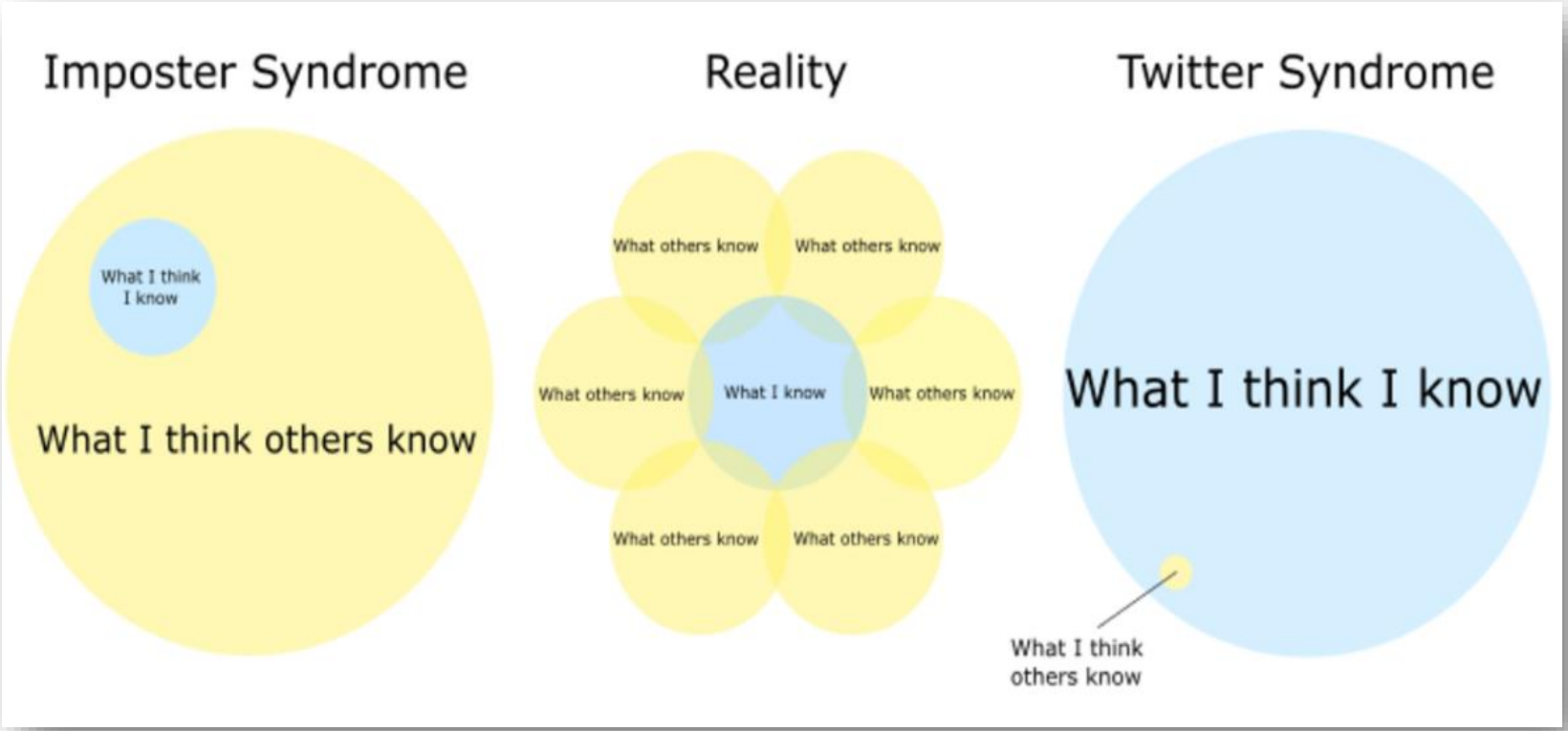
1. Background

“Suzanne Imes, Ph.D., and Pauline Rose Clance, Ph.D., first coined the term in 1978 to describe a **feeling shared by high-achieving women** and other successful individuals from marginalized groups. It’s since expanded to also commonly affect high-achieving individuals, particularly those in academics and the healthcare field.” Imposter Syndrome: Signs, Causes And Solutions – Forbes Health

2. Definition

“Imposter syndrome, also referred to as imposter phenomenon, is a **pervasive feeling of self-doubt** surrounding an individual’s intelligence, abilities and accomplishments—even when the individual has demonstrated competence in the past.” Imposter Syndrome: Signs, Causes And Solutions – Forbes Health




Imposter Syndrome
What I think I know
What I think others know
Reality
What others know
What others know
What others know
What I know
What others know
What others know
What others know
Twitter Syndrome
What I think I know
What I think others know

Imposter Syndrome and Pretending

3. Neg Experiences/Pos Outcomes

- Sometimes, we experience the difficulties of Imposter Syndrome regarding our own stories

- We do this by either:
  - Believing that the **positive outcome isn't really that valuable**
  - We don't fully **understand how it could be relevant**
  - We **minimize the truth** of what we have experienced, especially when compared to other people's stories

- It is possible to experience Imposter Syndrome about our negative experiences as well as our positive ones

Imposter Syndrome and Pretending

4. “We Are What We Pretend To Be”

“This is the only story of mine whose moral I know. I don’t think it’s a marvelous moral; I simply happen to know what it is: We are what we pretend to be, so we must be careful about what we pretend to be.”

-Kurt Vonnegut, Mother Night

- We feel like we are pretending when in reality, we aren’t
- Feeling like your pretending is very similar to the feeling of retelling what happened
- Our character and values are exhibited in the stories we tell and the actions we take
- By sharing our own stories, we are sharing our values of authenticity and vulnerability

Let’s discuss YOUR story…

How do you develop your anchor story?

It’s easy to think that other people won’t be interested in your story, that your lived experience was so personal that it could never be relatable.

It starts with small steps:

1. Start small with one part of your anchor that you think might be relevant for the work you do.

2. Share your stories with someone in a confidential setting first and get their feedback, gauge their reactions, and enlist them in your effort to improve.

Dave in Three Parts

1. Came out in early 80's

During the first signs of an epidemic

2. Change therapy

Shame regarding my sexual orientation

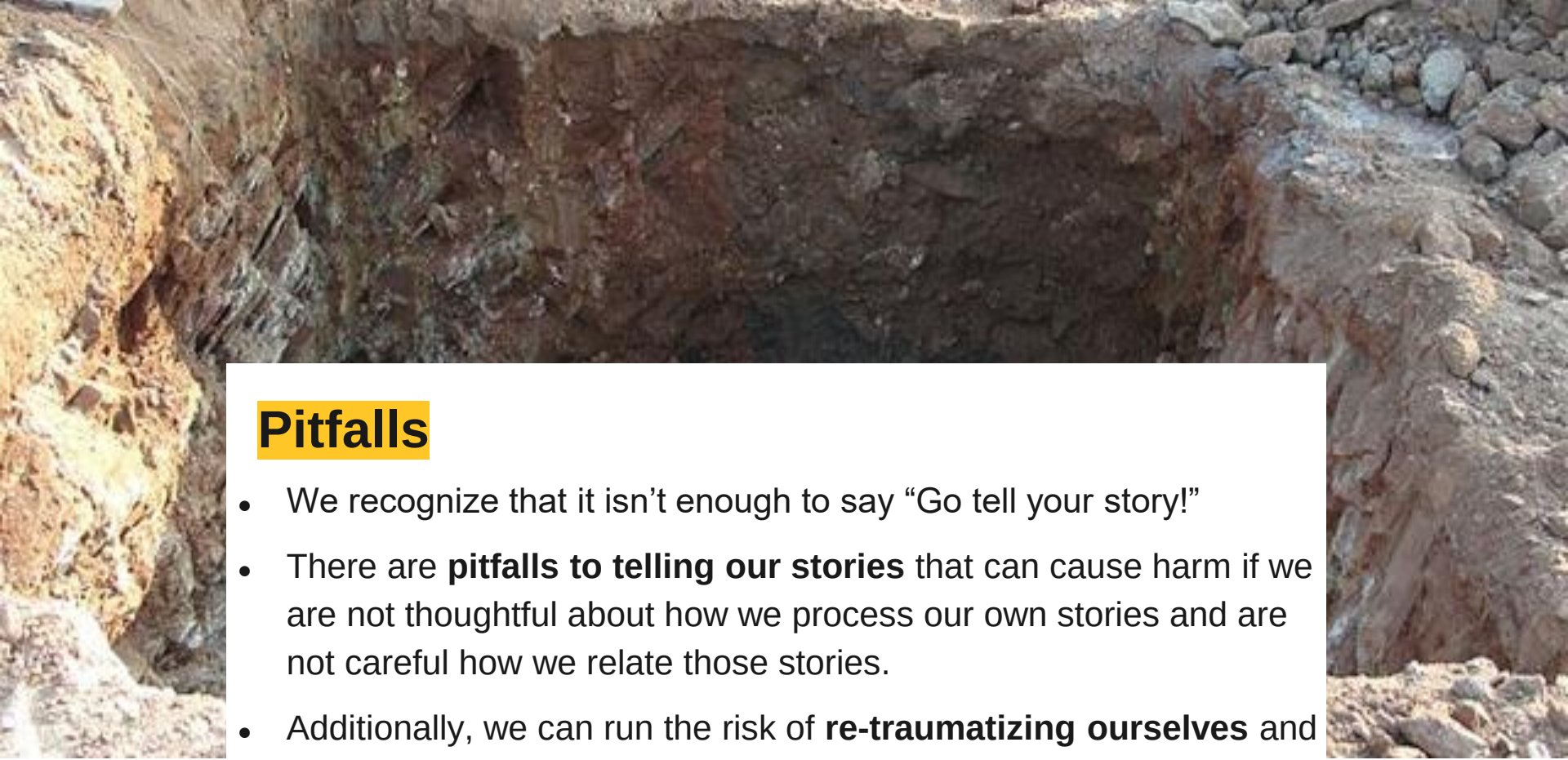
3. Passionate about HIV

I had the privilege of learning that HIV was a virus and not something to judge someone about.

Activity

Telling your story

- Thinking about your “why,” **write down key points of your story** that can be told in three minutes or less.
- Think about **when you would tell your story**, what are your boundaries? How transparent do you want to be?
    - **Is your story valid even if you aren’t ready to share it with others?**
- IF you are comfortable, **share your story with the person sitting next to you in 3 minutes or less,** then switch and repeat.



Pitfalls

- We recognize that it isn't enough to say "Go tell your story!"
- There are **pitfalls to telling our stories** that can cause harm if we are not thoughtful about how we process our own stories and are not careful how we relate those stories.
- Additionally, we can run the risk of **re-traumatizing ourselves** and the people we are trying to serve if we "misread" the room.
- Context is everything!

Storytelling and the The Law of Unintended Consequences

- **Storytelling is**, by nature, a form of **“outing”** oneself. We are revealing things that may not otherwise be known.
- There are **inherent risks** of the story being interpreted through other people’s personal experiences and filters, of people not getting the connection to the topic at hand, and of not being able to put the information back in the box.
- **De-briefing** can be helpful!
- Safety can be an issue, and **it can feel unsafe** when we share stories that we aren’t ready to tell.
    - How do we develop our own stories about background, culture, and experiences so that we create safe spaces for ourselves and others?

Benefits of Sharing Our Stories

- **We give others the space to share theirs, too!**
- **We remind ourselves of our anchors and whys…**
- **We process our history and reframe it…**
- **We increase patient/client satisfaction by building relationships through shared experiences…***
- **We become the HERO of our own stories by acknowledging and celebrating those parts of us we usually hide, and encourage others through our own journeys**

*According to a 2022 study published in the *International Journal of Pharmaceutical and Healthcare Marketing*, patient satisfaction can be greatly improved by relationship-oriented marketing powered by storytelling.

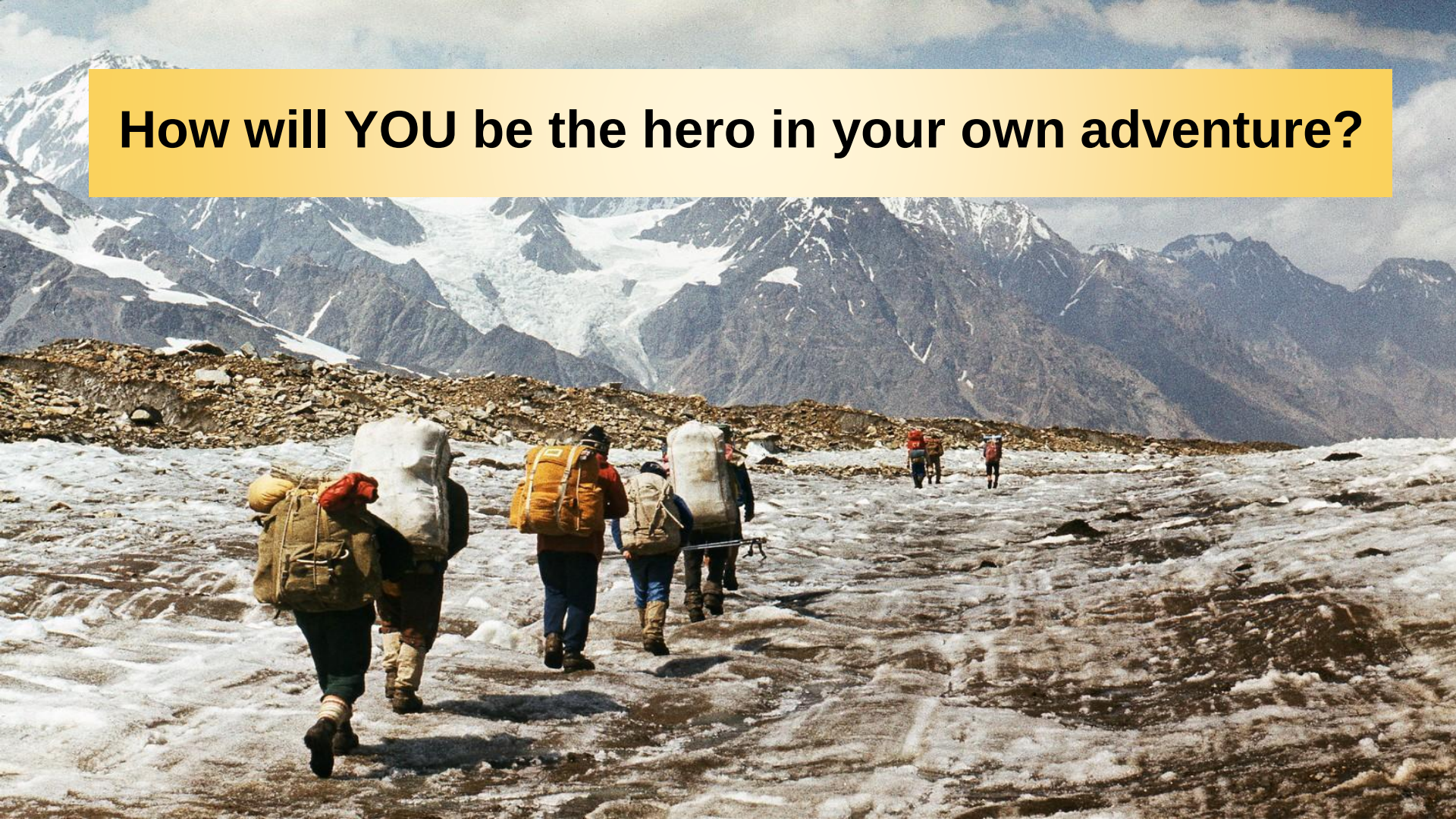
Conclusion

Next Steps for Living Your Truth

- What is your story and how will you use it to improve health equity??

- What are your next steps for embracing transparency and telling your own story?

How will YOU be the hero in your own adventure?



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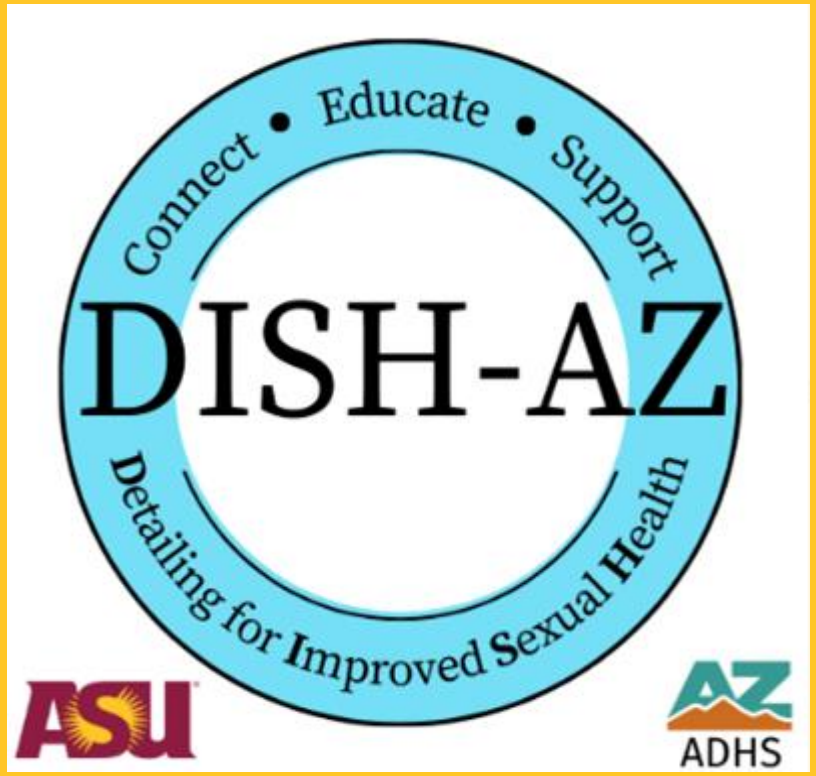

Our Weekly Newsletter

Individualized and ongoing education and connections for Arizona healthcare providers.