

# *Centering the Disability Experience: Normalizing Sexuality*

*Rachel Kaplan, MPH – Kintsugi Consulting, LLC*



Kintsugi Consulting, LLC



# *Kintsugi Consulting, LLC*

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*Disability Consultation Services*





# Rachel Kaplan (She/Her)

Founder & Independent Disability Consultant

- Master Degree in Public Health and Master Certificate in Drug and Addiction Studies
- Over 10 years of experience working with:
  - Disability Advocacy
  - Program Management
  - Homeless Population and Medical Adherence
  - Type 1 and Type 2 Diabetes
  - Domestic Violence Awareness,
  - Sexual Assault and Rape Crisis Support Services
  - Mental Health Advocacy
- Experienced Public Speaker
- Person living with a Disability: chronic health



- National Independent Living Council (NCIL): Member
- Association of Programs for Rural Living (APRIL): Peer Mentor
- Advisory Board Member, Adjunct Trainer and Contract Employee: Elevatus Training
- Advisory Board Member: The Hive Community Circle
- Board Member: Mental Health America Greenville Co.
- Co-Founder: Evidence Informed Sustainability Project, Diabetes Family Connection
- Family Representative: The Family Support Network of The Greater Triangle Area



# Effy Francis (They/Them or He/Him)

Content Reviewed by: Disability Activist & Self Advocate

- Multiply disabled, including physical, developmental, and neurodivergent disabilities
- Over 4 years experience working with:
  - Disability Advocacy
  - Youth Programming
  - Peer Support
  - Sexual Health Advocacy
  - LGBTQIA+ Intersectionality/Disability Justice
- Experienced Public Speaker



- Boards & Committees Experience:
  - SC Statewide Independent Living Council (SILC): Secretary
  - SC Youth Leadership Forum (YLF): Peer Mentor
  - SC State Alliance for Adolescent Sexual Health (SAASH): Member/Disability Advocate
  - State Coalition for Youth Empowerment & Access (SCYEA!): Member/Disability Advocate
  - National Independent Living Council (NCIL) Youth Caucus: Member
  - Kids As Self Advocates (KASA): Member



# Kintsugi (kin-sue-ghee)

Japanese Art Form



Kintsugi (Kin-sue-ghee) is the Japanese tradition and art of mending broken pottery.

The cracks created when something is broken are filled with gold or silver so that the item can still be used moving forward.

This art form encourages growth, acceptance of flaws, and the opportunity to see the beauty in diversity.





# Topics to Cover for Today:

- Overview of Disability and Harm Reduction
  - Impact vs. Intention
- Implicit Bias and Stigma Towards the Disabled Community
- Common Myths and Stigmas
  - The Concept of Consent
  - Self-Advocacy vs. Youth-Advocate
- Intersection of Disability and:
  - LGBTQ Population
  - Sexuality
  - Sexual Violence/Abuse
- Vulnerable vs. Uninformed
- Next Steps - What Can You Do?





**Why Do I Need to Be Aware of Disability Inclusion?**

**How Does This Apply to ME and the Work I Do?**



From 2015 through 2019, just over 210,000 persons with one or more disabilities resided in Maine

- This is equal to about **16% of its civilian non-institutionalized population of 1.3 million.**
- This proportion was higher than that of the United States, where an estimated 13% of residents had a disability.

In Maine and the U.S., about half of residents with a disability are of working age (18 to 64 years)







In 2019–20, the number of students ages 3–21 who received special education services under the Individuals with Disabilities Education Act (IDEA) was 7.3 million, **or 14 % of all public school students.**

In Maine, students enrolled in Special Education Services:

- In middle school are between 8.6% – 8.8% of the 12-14 age range group of school-age students
- In high school are between 7%-8.2% of the 15-17 range group of school-age students



# *Assessing Your Comfort Level with Disability*

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Discussing a topic you feel uncomfortable speaking on can be scary. It's almost like jumping off the high dive into a pool of water without feeling prepared!

Imagine the pool as situations that will involve disability awareness, inclusion, knowledge, and education. What will help you get to the point where you climb up the ladder with abandon and dive off?

The only way to grow in skill and confidence is to assess where you're going and where you want to end up!



# Levels of Comfort

**Diving off the Diving Board:** You feel confident coaching others

**Standing on the Diving Board:** You have been in this situation many times before and feel confident addressing this solo

**Rung 9**

**Rung 8**

**Rung 7**

**Rung 6**

**Rung 5:** Somewhat comfortable in this situation with support

**Rung 4**

**Rung 3**

**Rung 2**

**Standing on the Ground:** Not at all comfortable in this situation



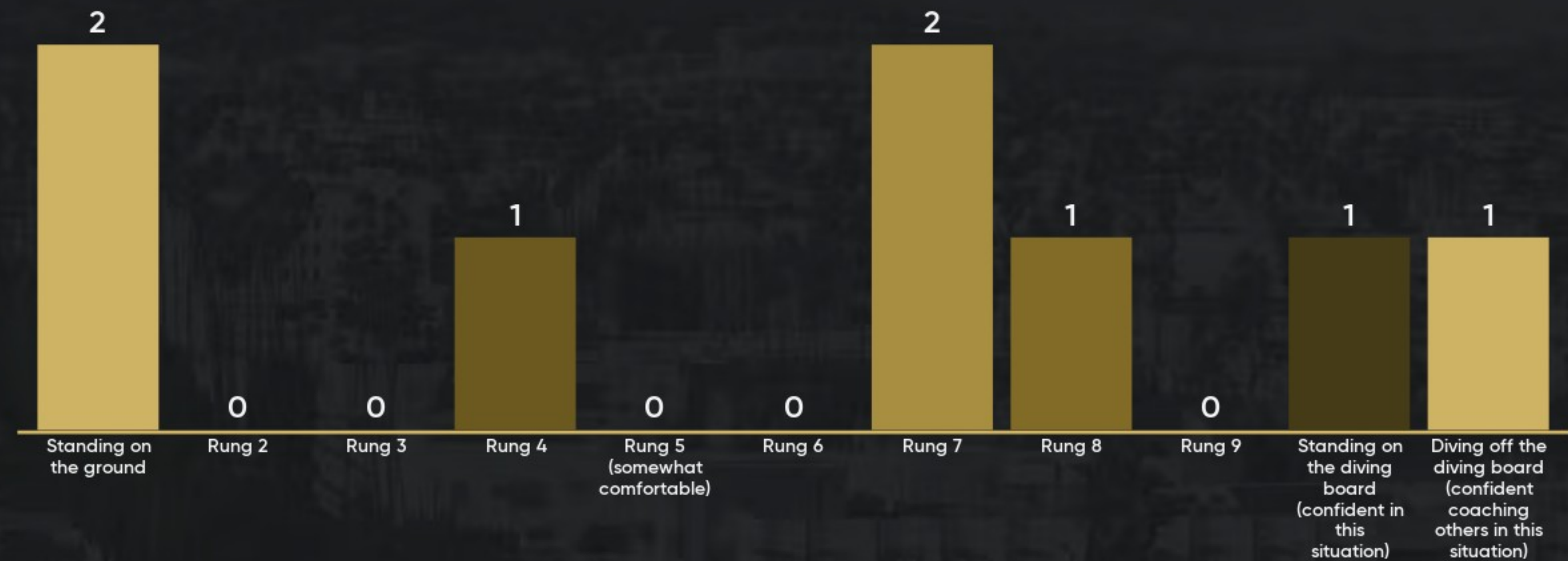
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# WHAT IS YOUR COMFORT LEVEL WITH ANSWERING HONESTLY WHEN SOMEONE ASKS IF THEY HAVE A DISABILITY?





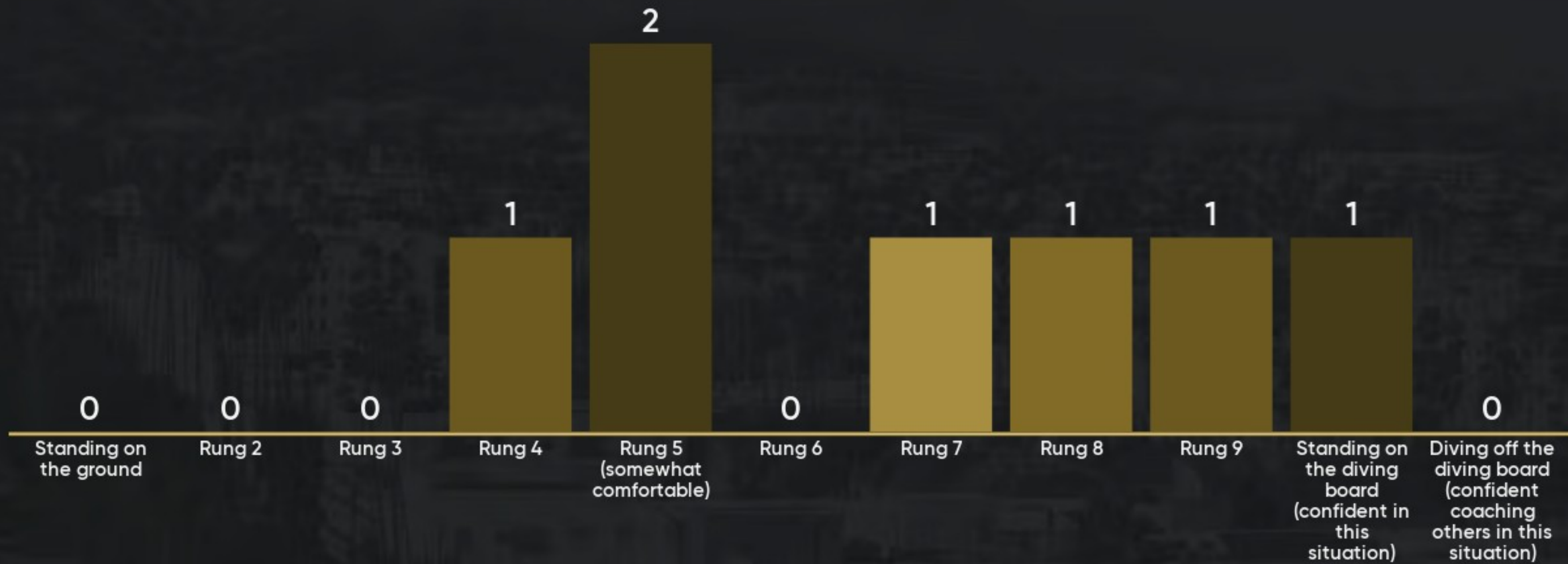
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# WHAT IS YOUR COMFORT LEVEL WITH UNDERSTANDING WHAT A REASONABLE ACCOMMODATION IS?





# Levels of Comfort

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# WHAT IS YOUR COMFORT LEVEL WITH ADAPTING CONTENT TO BE DISABILITY FRIENDLY?





# Levels of Comfort

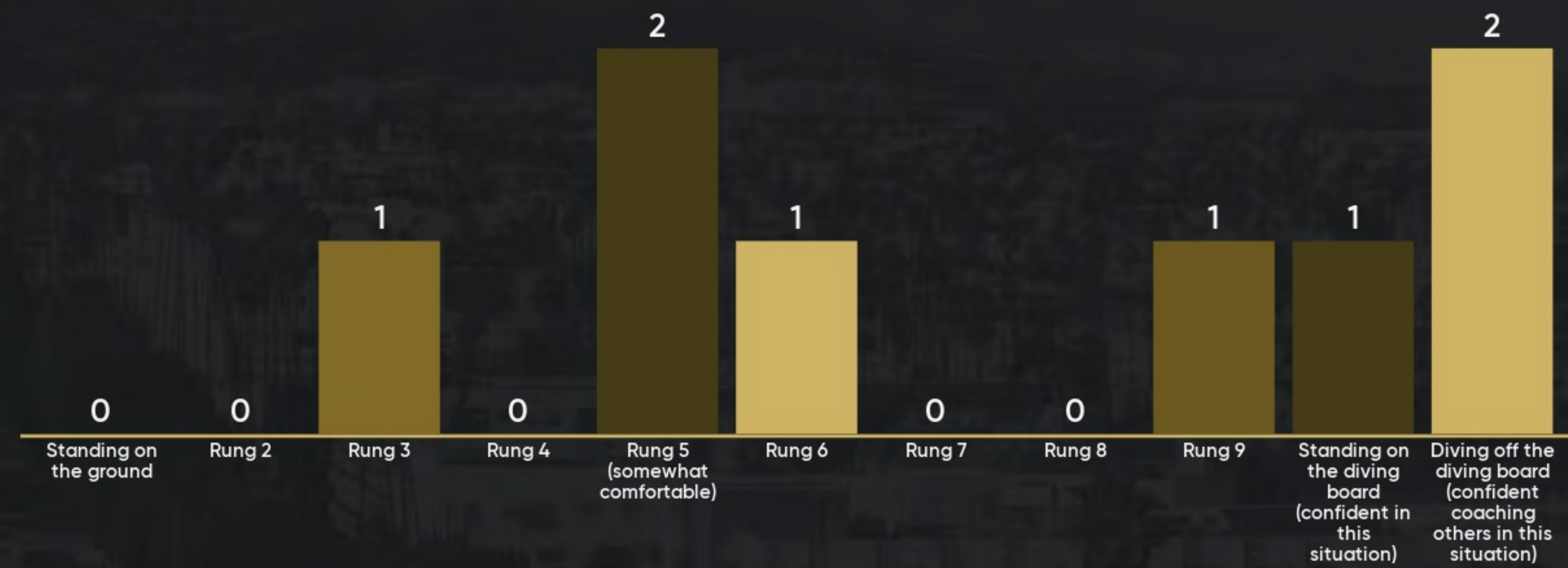
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# WHAT IS YOUR COMFORT LEVEL WITH DISCUSSING DIFFERENT TYPES OF DISABILITIES?





# Levels of Comfort

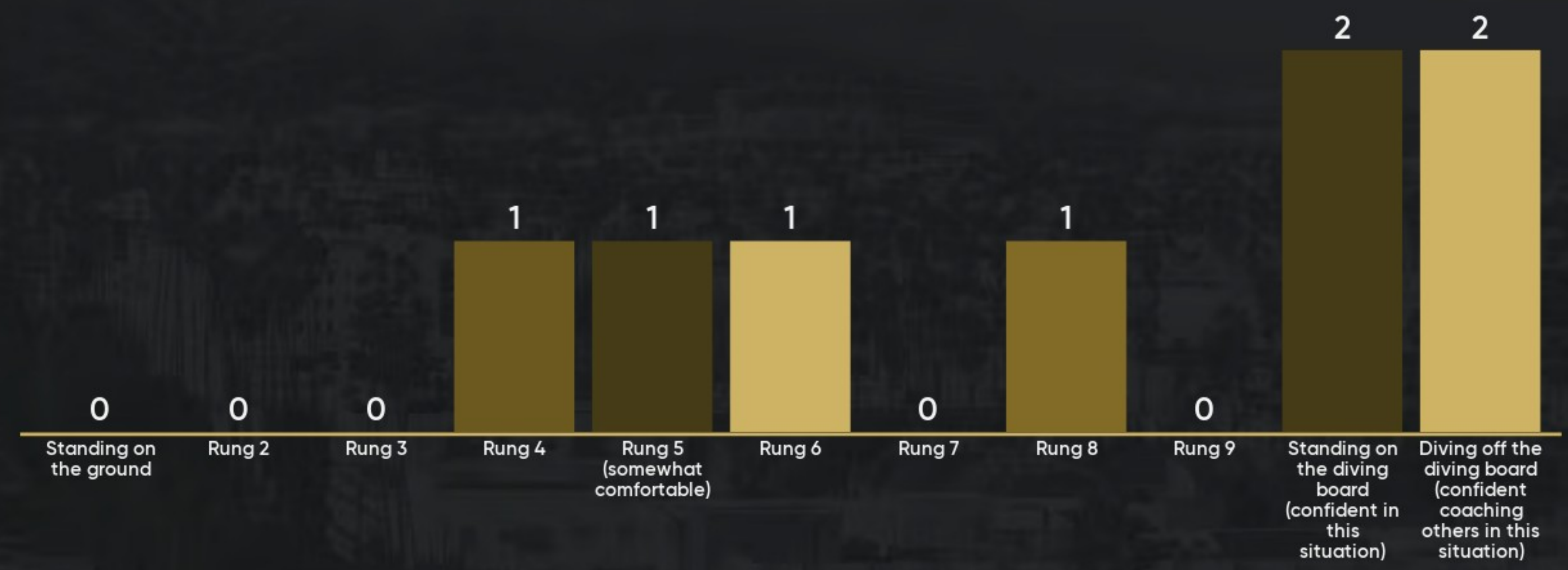
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# WHAT IS YOUR COMFORT LEVEL WITH READING THROUGH AN IEP (INDIVIDUALIZED EDUCATION PLAN)?





# Levels of Comfort

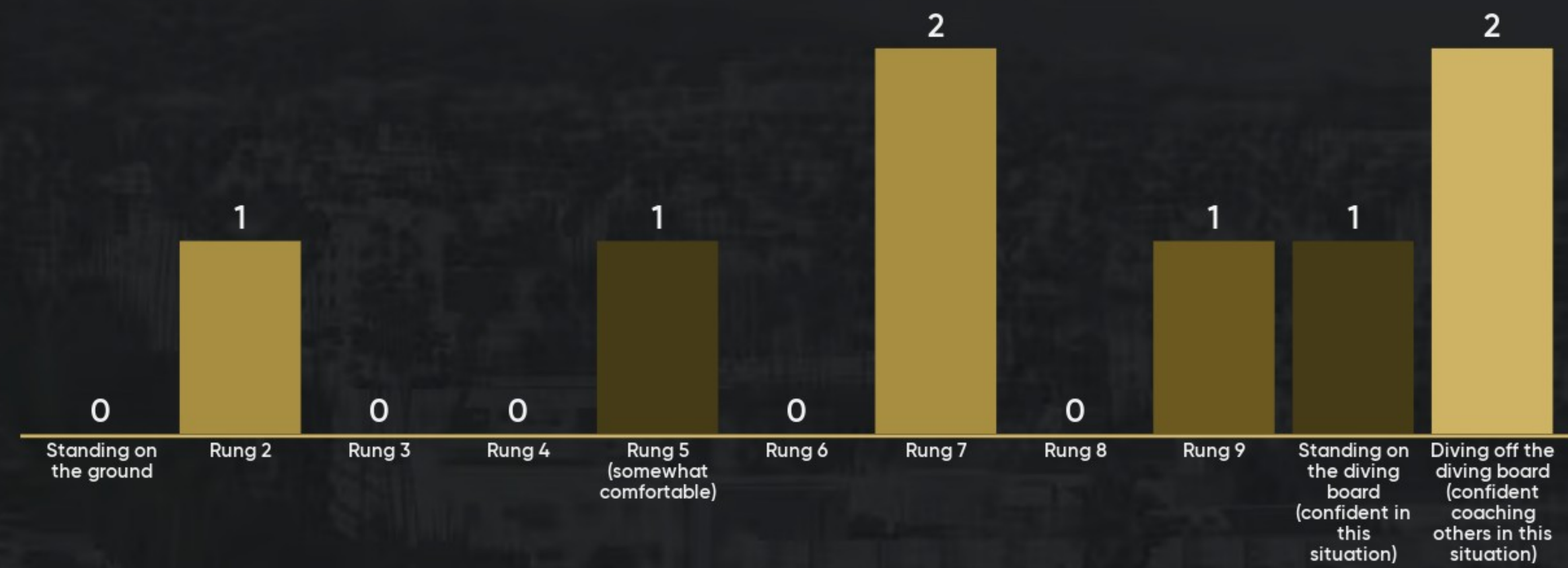
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# WHAT IS YOUR COMFORT LEVEL WITH EDUCATING PEERS ABOUT ACCOMMODATIONS?





# Levels of Comfort

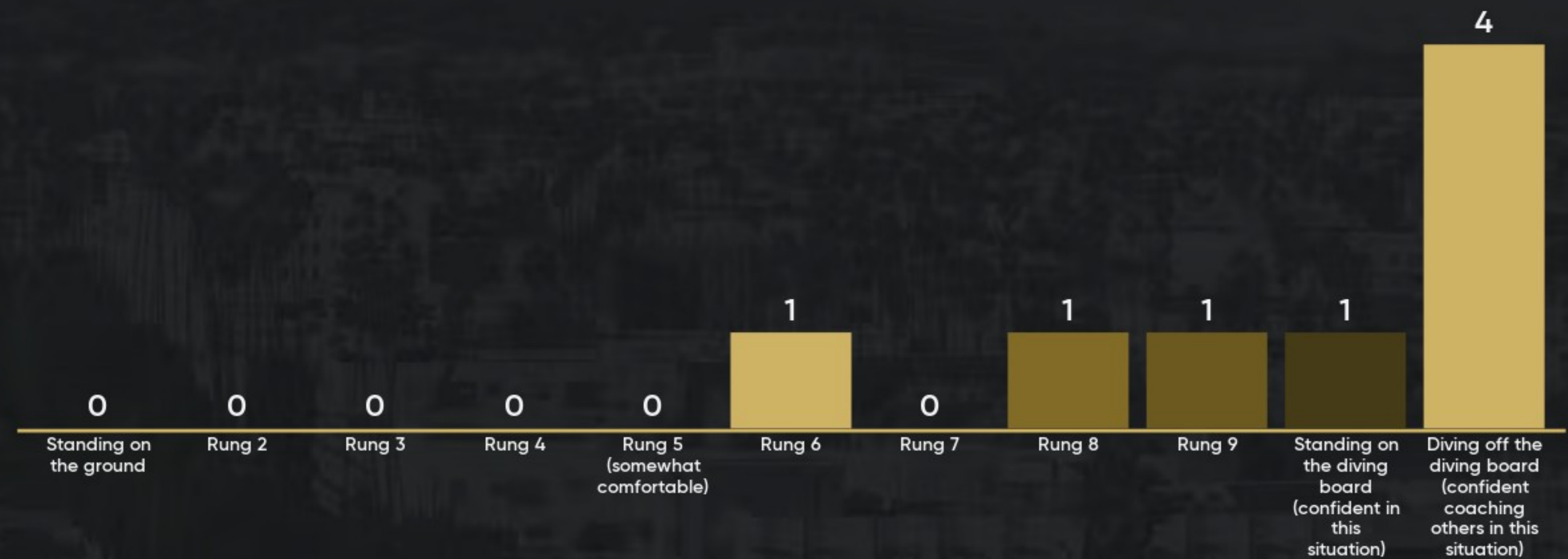
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# WHAT IS YOUR COMFORT LEVEL WITH HAVING A CLASS-WIDE DISCUSSION ABOUT DISABILITY, DIFFERENCES, SIMILARITIES, AND RESPECT?





# Levels of Comfort

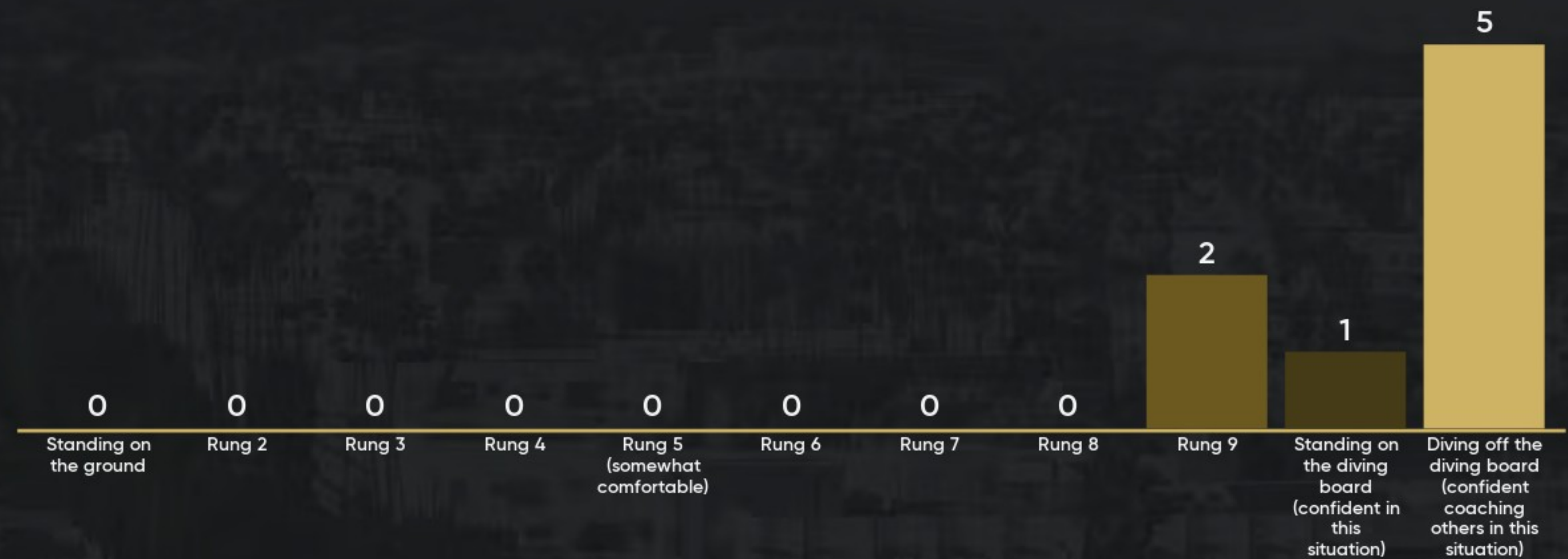
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**the Ground:** Not at all comfortable in t

## WHAT IS YOUR COMFORT LEVEL WITH SAYING "I DON'T KNOW" IF ASKED A QUESTION ABOUT DISABILITY YOU DON'T KNOW THE ANSWER TO?





# Levels of Comfort

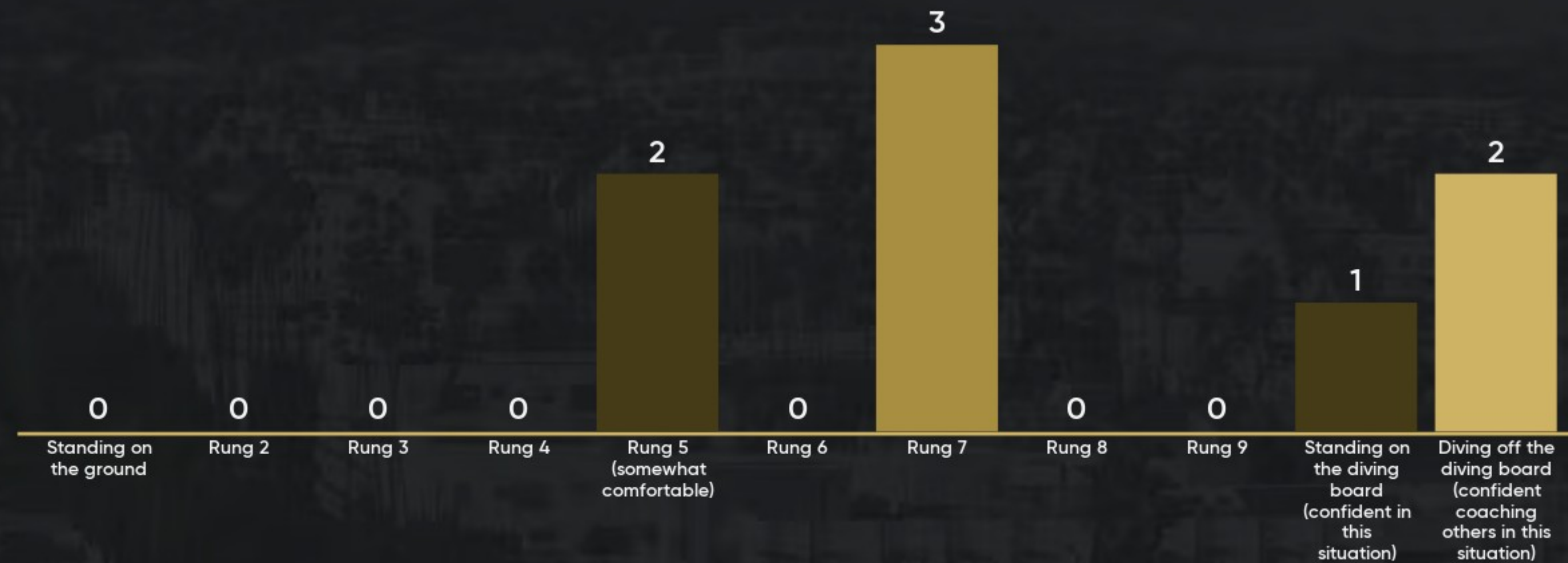
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# WHAT IS YOUR COMFORT LEVEL WITH TALKING TO A PERSON WITH A DISABILITY ABOUT SEXUAL AND REPRODUCTIVE HEALTH?





# Levels of Comfort

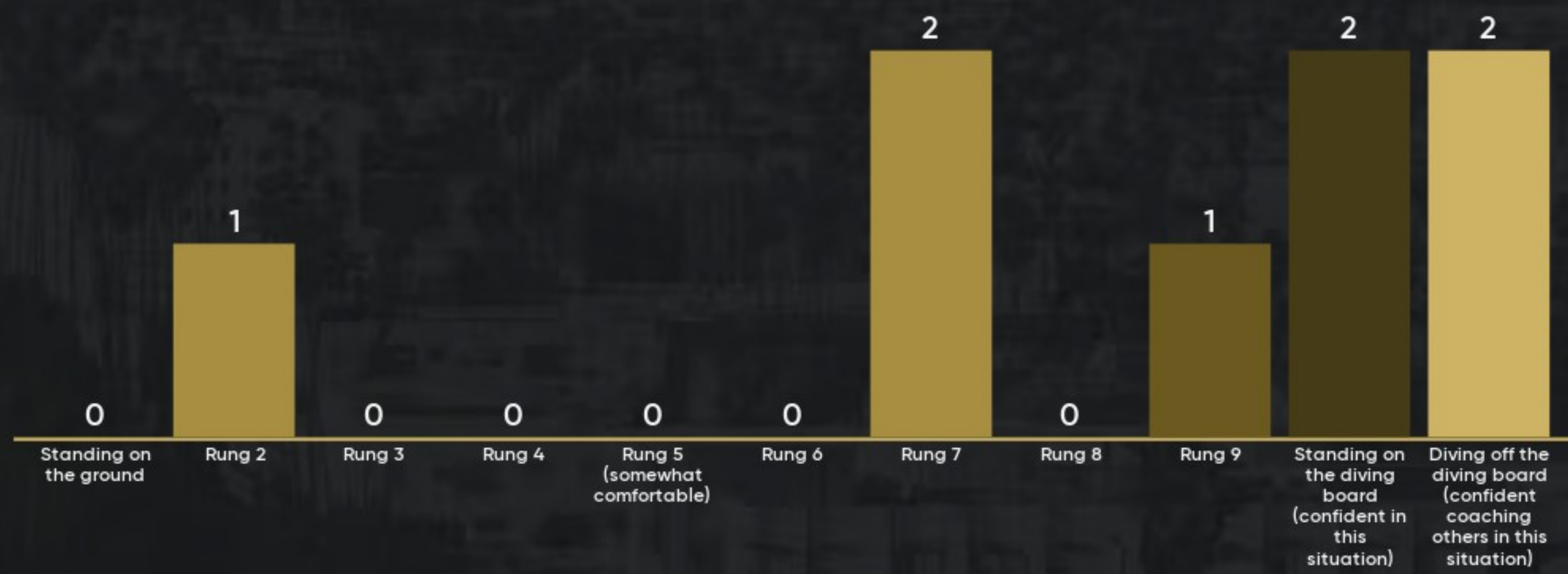
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## WHAT IS YOUR COMFORT LEVEL WITH WORKING WITH A YOUNG PERSON ON THEIR PLANS FOR THE FUTURE THAT ARE BOTH AFFIRMING AND REALISTIC?





# WHAT IS ONE STATEMENT YOU FELT THE MOST COMFORTABLE WITH?

It's easy for me to say "I don't know."

Talking with young people about sexuality

Saying I don't know

Being honest about their disability.

Making accommodations



# WHAT IS ONE STATEMENT THAT MADE YOU NERVOUS OR UNCOMFORTABLE?

I felt like I had lots of "well, it depends" reactions...

None

Being honest and realistic about their abilities

Being realistic about their dreams!



# WHAT HAS THIS ACTIVITY TAUGHT YOU ABOUT YOURSELF THAT YOU CAN FOCUS ON MOVING FORWARD?

More education to feel  
confident answering  
questions regarding  
disabilities.

Made me think about  
who to ask for help

Learning skills and  
language for talking to  
people with disabilities  
about sexuality

Believing I can do this  
work

I want to focus on  
learning more about  
sexuality to help  
educate students,  
parents and providers



# WHAT WORD(S) WOULD YOU USE TO DEFINE THE WORD "DISABILITY"?

summit  
same differently able  
love alternative learning resourceful  
diverse  
beautiful limited  
ability  
learn  
special  
marginalized  
challenges  
unique  
strength  
self aware  
positive  
joy  
explore  
value neutral  
uniqueness  
different  
differenced learning  
not always physical  
opportunities  
shine  
struggle





# Disability

ADA defines disability as a mental or physical impairment that substantially limits or impacts one or more major life activities that impact daily living.

This can include someone who:

- Has a history or record of an impairment
- Is a person who is perceived by others to have an impairment

The ADA does not specifically list out all impairments that fall under the disability category, however disability categories often include:

- Physical
- Chronic Health Condition
- Emotional
- Mental Health
- Intellectual
- Developmental
- Visual
- Auditory

# Harm Reduction

Aims to decreasing adverse (negative) consequences or outcomes for those with disabilities:

- Policies
- Behaviors
- Social consequences
- Economic consequences

For today's purposes, harm reduction focuses on reducing negative outcomes related to perception of people with disabilities.

- Stereotypes
- Assumptions
- Narrative creation about a person's experiences/diagnoses



# Implicit Bias 101: Disability Population

- Stereotype-confirming thoughts
  - When your brain notices patterns and establishes generalizations
  - These generalizations lead to overgeneralization – which creates bias and discrimination
- People with implicit bias are not outwardly prejudiced
  - Thoughts and subconscious behavior are learned early and can carry through adulthood



# *Intention vs. Impact*

“The overall message in all of these conversations is that when someone does something hurtful or offensive to another person, the [committer's] intent is not what's most important when gauging the appropriateness of an action -- in fact, many would say that it is inherently privileged to redirect the focus of a conversation to the [committer's] (presumably harmless) intentions, rather than focusing on the feelings and experiences of the person who has been harmed.

So, the point is that we really need to focus on *impact*, not intent.

Was someone hurt by something?

Was there a negative outcome?

Did someone suffer?

If so, that is what's important.”

- Melanie Tannenbaum



# *Addressing Myths and Stereotypes*

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*Inaccurate Assumptions and How They Negatively Impact People with Disabilities*



# True or False Activity

## *Common Thoughts*

Let's look at some statements regarding people with disabilities.

What might impact our answers?

- Knowledge of disability history
- Personal comfort levels
- Personal values/beliefs
- Community values/beliefs
- Societal values/beliefs

## *Is It True? Is It False?*

When deciding if this statement is true or false, keep the following in mind:

- Is this true of an entire population?
- Am I basing my answer on someone I know personally or my own personal values/beliefs?
  - Is that putting a limitation on a whole population of people?
  - Is this enhancing my understanding of common myths or stigmas?

## *Exceptions to the Rule*

For any general rule or statement, there is the possibility of exceptions.

There may be some individuals who fall outside of the true/false statement.

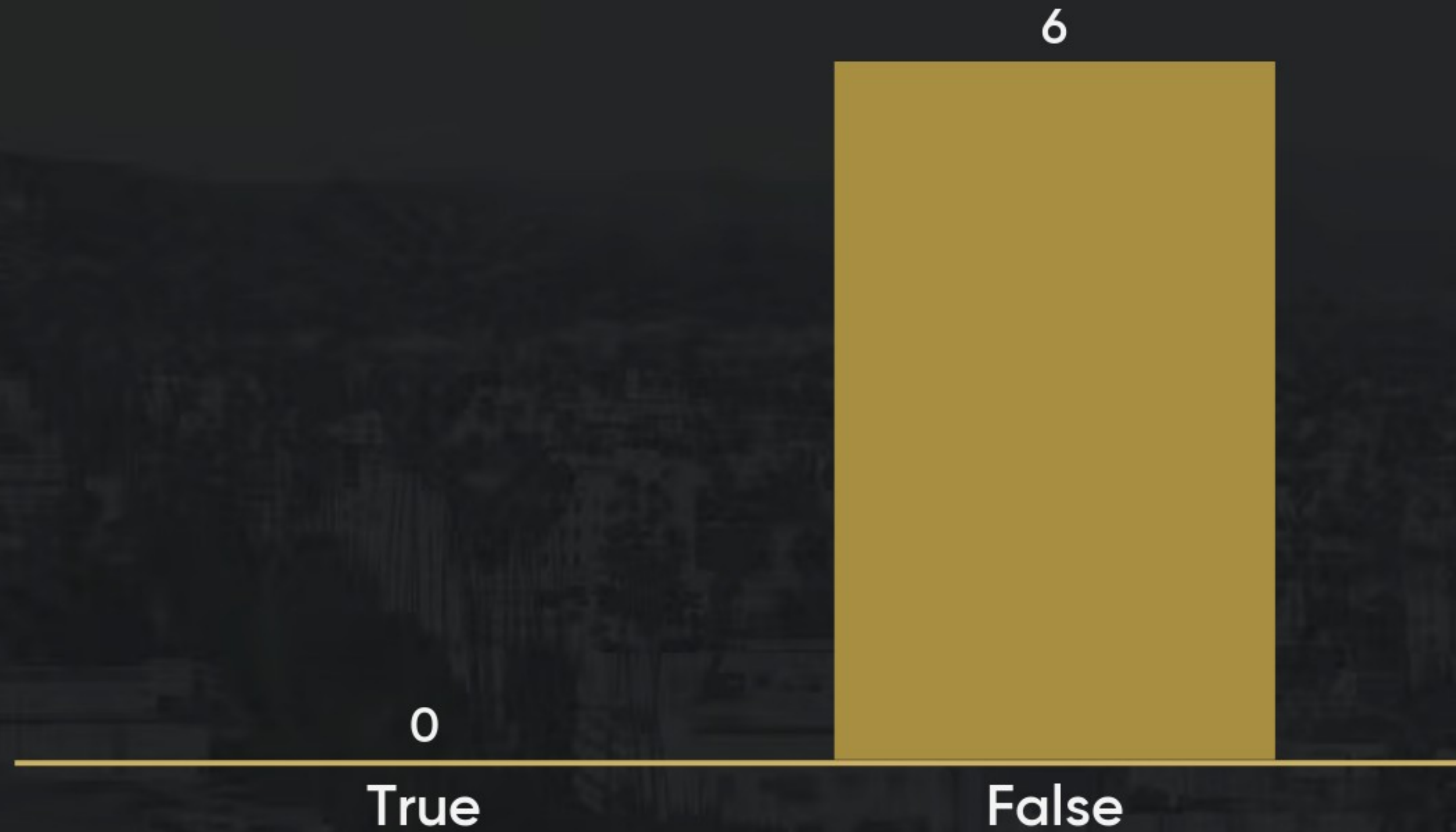
This is OKAY.

People with disabilities are all independent of each other – what works for one, may not work for another. The road to success will look different for everyone.

This is EXPECTED\*\*\*



# TRUE OR FALSE: PEOPLE WITH DISABILITIES CANNOT GIVE CONSENT.







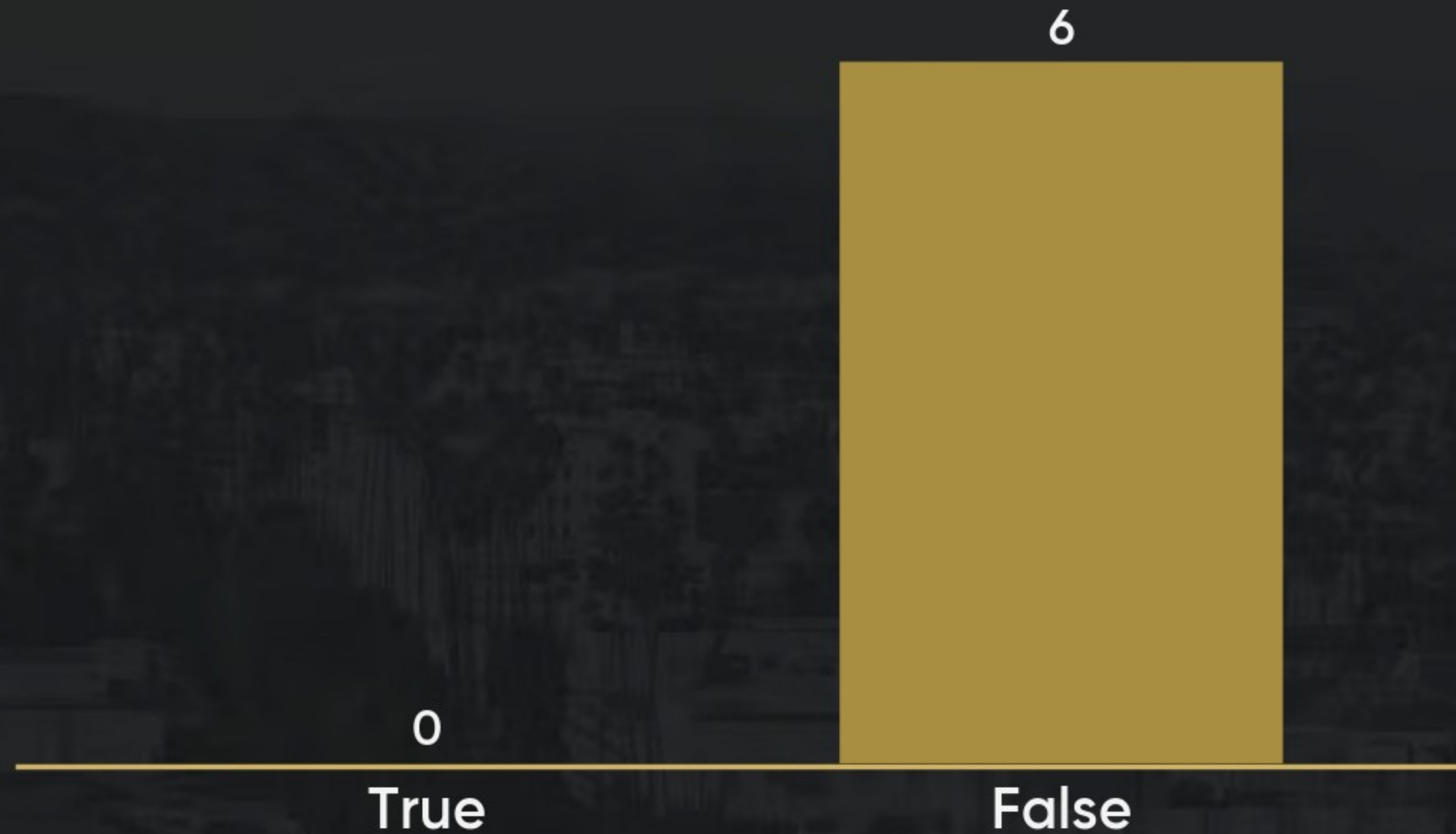
# Self-Advocacy and Decision-Making

## Self-Advocacy:

- (1) Knowing what you want as a unique individual = making decisions
- (2) Expressing those needs and wants to others based on your own discretion
- (3) Asking for assistance and support when it is needed

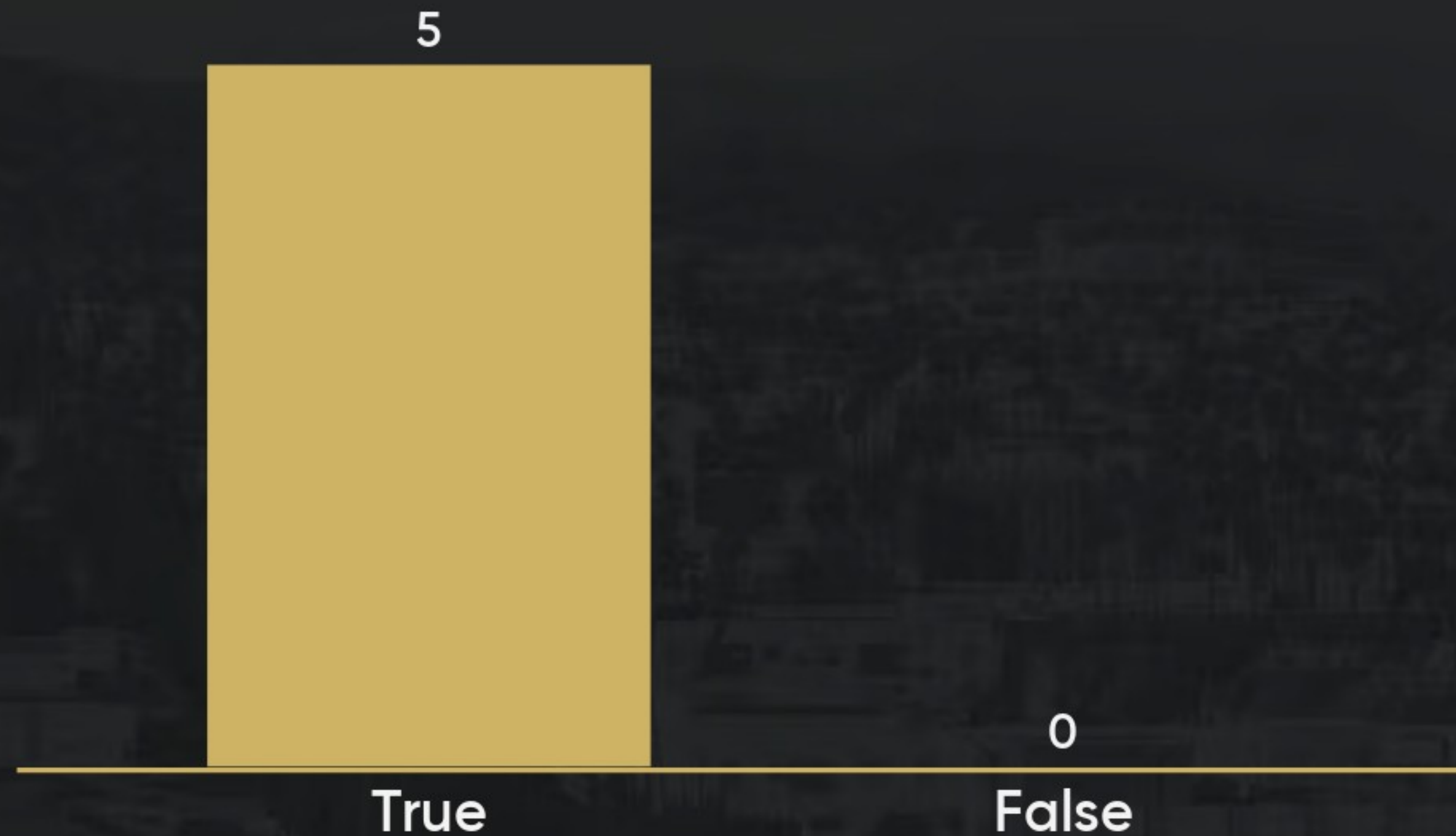


**TRUE OR FALSE: PEOPLE WITH DISABILITIES CANNOT UNDERSTAND SOMEONE WITHOUT A DISABILITY.**





**TRUE OR FALSE: PEOPLE WITH  
DISABILITIES CAN BE PART OF THE  
LGBTQ+ COMMUNITY.**





## AN ESTIMATED 3-5 MILLION LGBT PEOPLE HAVE DISABILITIES



&amp;

**2 in 5**transgender adults<sup>1</sup>**1 in 4**LGB adults<sup>2</sup>  
in California**40%** of bisexual men**36%** of lesbian women**36%** of bisexual women**26%** of gay men<sup>3</sup>  
in Washington

reported having a disability

...compared to **27.2%**  
of the general population<sup>4</sup>

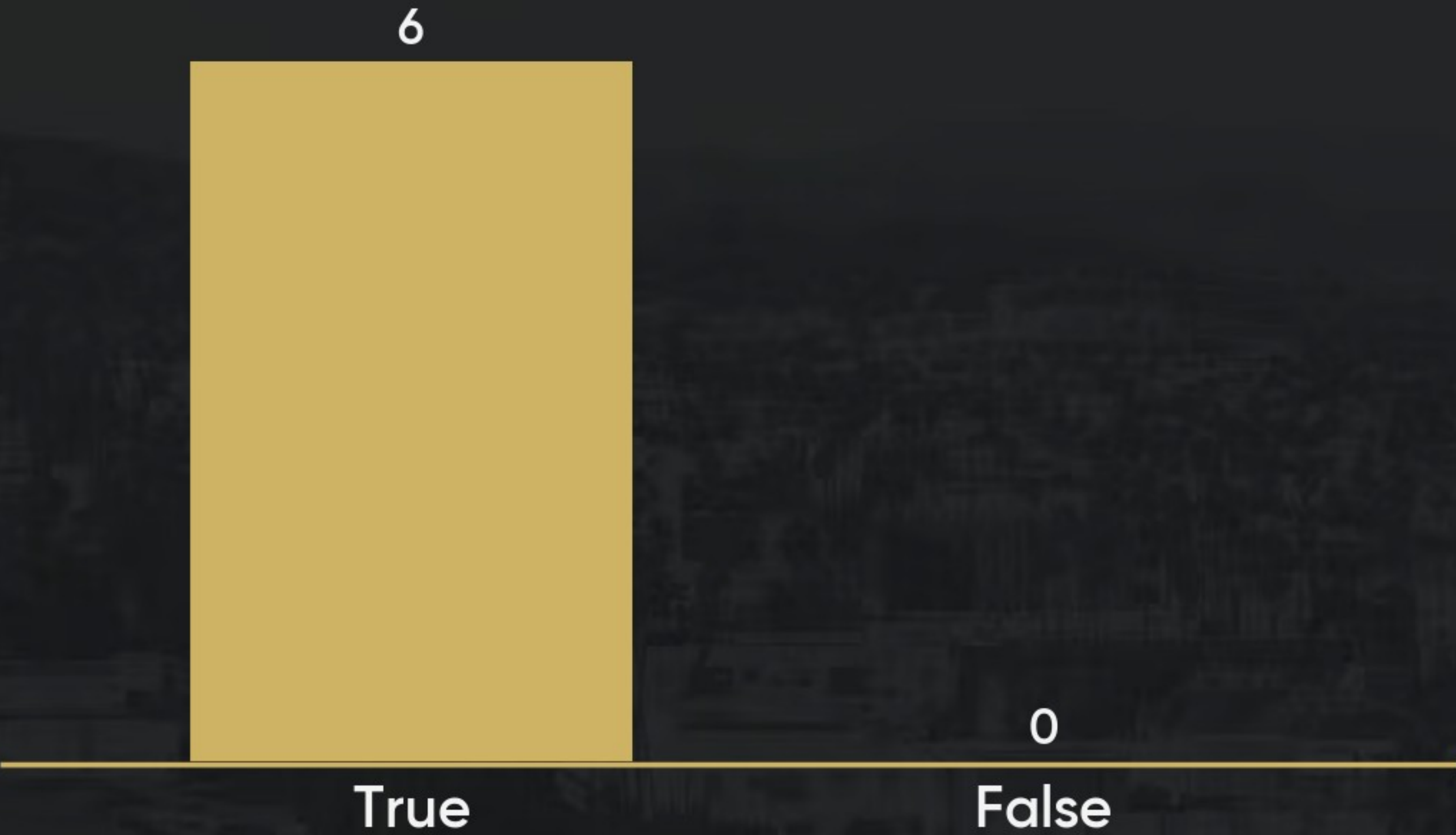
Note: current estimates suggest there are between 9-11 million LGBT adults in the United States. Assuming that approximately one in four have a disability, we estimate there are between 3-5 million LGBT people with a disability.



*Content Warning:  
Mention/Statistics for Violent  
Crimes, Sexual Assault, and  
Domestic Violence*



# TRUE OR FALSE: PEOPLE WITH DISABILITIES HAVE SEXUAL URGES.



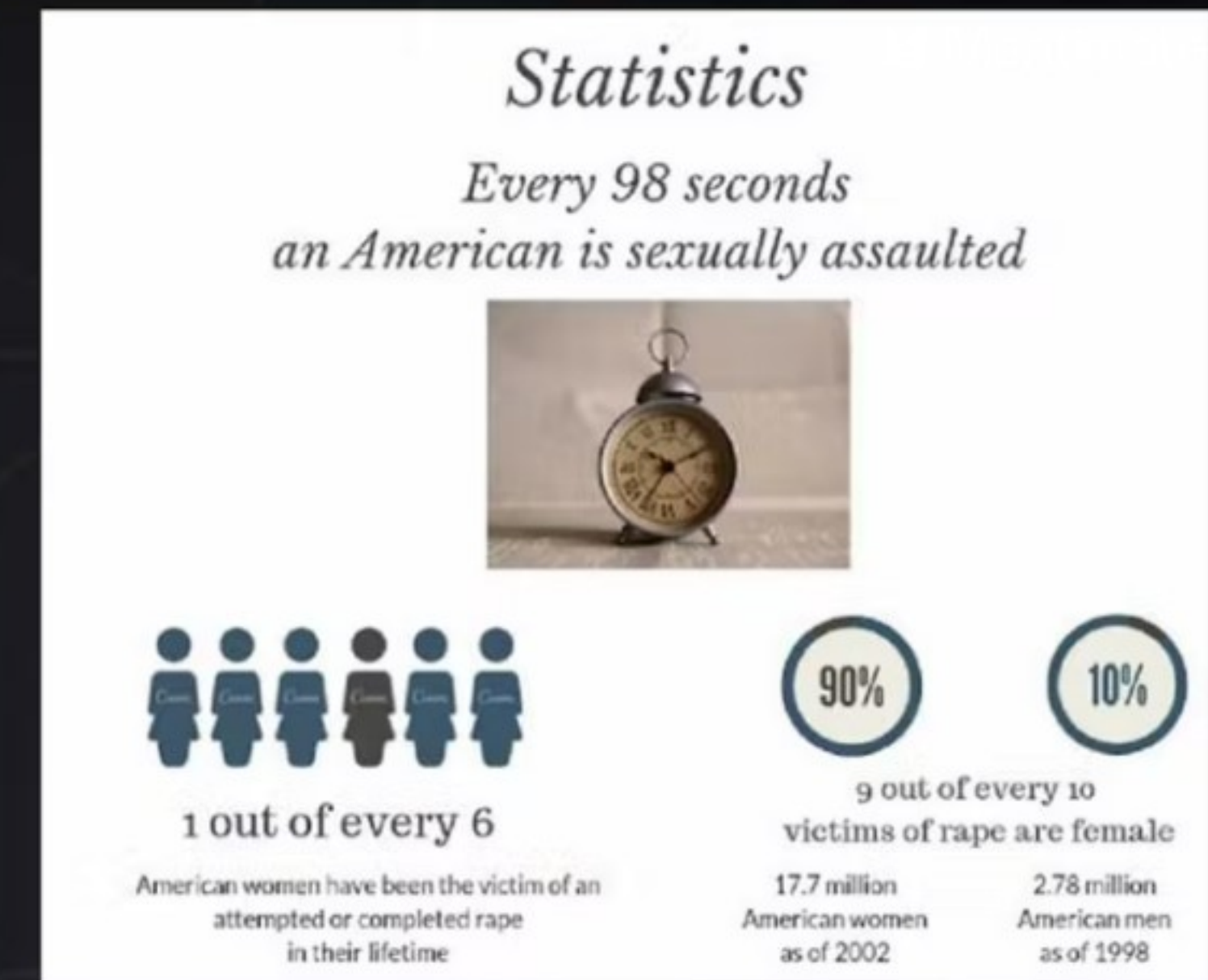


**TRUE OR FALSE: IT'S OKAY TO ABUSE  
PEOPLE WITH DISABILITIES; THEY DON'T  
UNDERSTAND WHAT'S HAPPENING  
ANYWAYS.**





# Let's Review Some Statistics:



- Maine currently ranks 16<sup>th</sup> in the nation for the rate of women killed by men (domestic homicide)
- Most of the time, women are murdered by men they know
- People with disabilities (not institutionalized) are 2-3 times more likely to experience violent crimes
- People with disabilities (not institutionalized) are at 40% greater risk of intimate partner violence, especially severe violence
- In 2018, data from people age 12+ showed that 31.8% of men with a disability experienced violent victimization, versus 14.1% of men without a disability
- In 2018, data from people age 12+ showed that 32.8% of women with a disability experienced violent victimization, versus 11.4% of women without a disability
- There is increased risk of violence for intersecting populations (BIPOC, LGBTQ+, non-citizens)



*Content Warning:  
Ableist Violence by  
Caregivers/Filicide*



# Why Does Disability Change Public Perception?

## Murder-Suicide: How Disabled People Feel



**Sarah Lerner**   
@SarahLerner

When you romanticize a man murdering his sick wife, you make misogynistic violence within intimate partner relationships between men and women acceptable. This is Exhibit A of how intertwined ableism and patriarchy is.  
[twitter.com/corinaknoll/st...](https://twitter.com/corinaknoll/status/1205123456789)

4:57 PM · Dec 29, 2019

11.8K 2.6K people are Tweeting about this



**Keah Brown**   
@Keah\_Maria

Me; stop romanticizing the murder of disabled/ill people  
Twitter: You have no idea the toll it takes to care for a disabled person!!! It's none of your business!  
Me, a disabled person: You have no idea how it feels to have your life boiled down to being WORTHY OF MURDER

10:08 AM · Dec 30, 2019

12.2K 2.5K people are Tweeting about this



**s.e. smith** @sesmith · Dec 29, 2019

Replying to @sesmith

It also has huge intimate violence implications which is something I NEVER see people talk about in cases like this. If a nondisabled person killed a nondisabled partner and then died by suicide, people would (rightly) be up in arms. So what changes with disability in the mix?



**s.e. smith**   
@sesmith

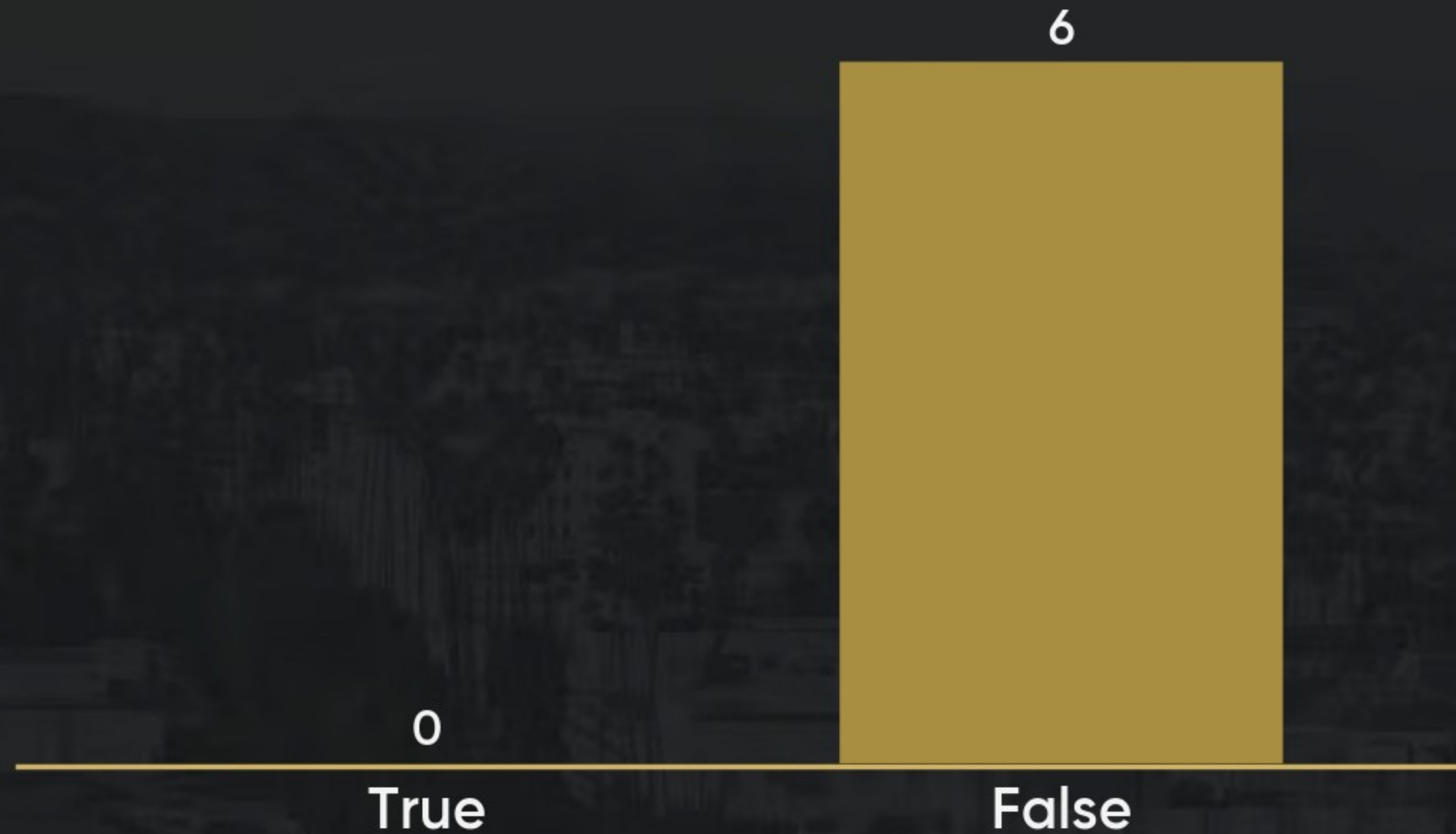
Disabled people are at radically increased risk of intimate violence, as well as financial control and other forms of abuse. Glossing over that in a story about a man who killed his wife is, if I may be blunt, pretty problematic.

2:54 PM · Dec 29, 2019

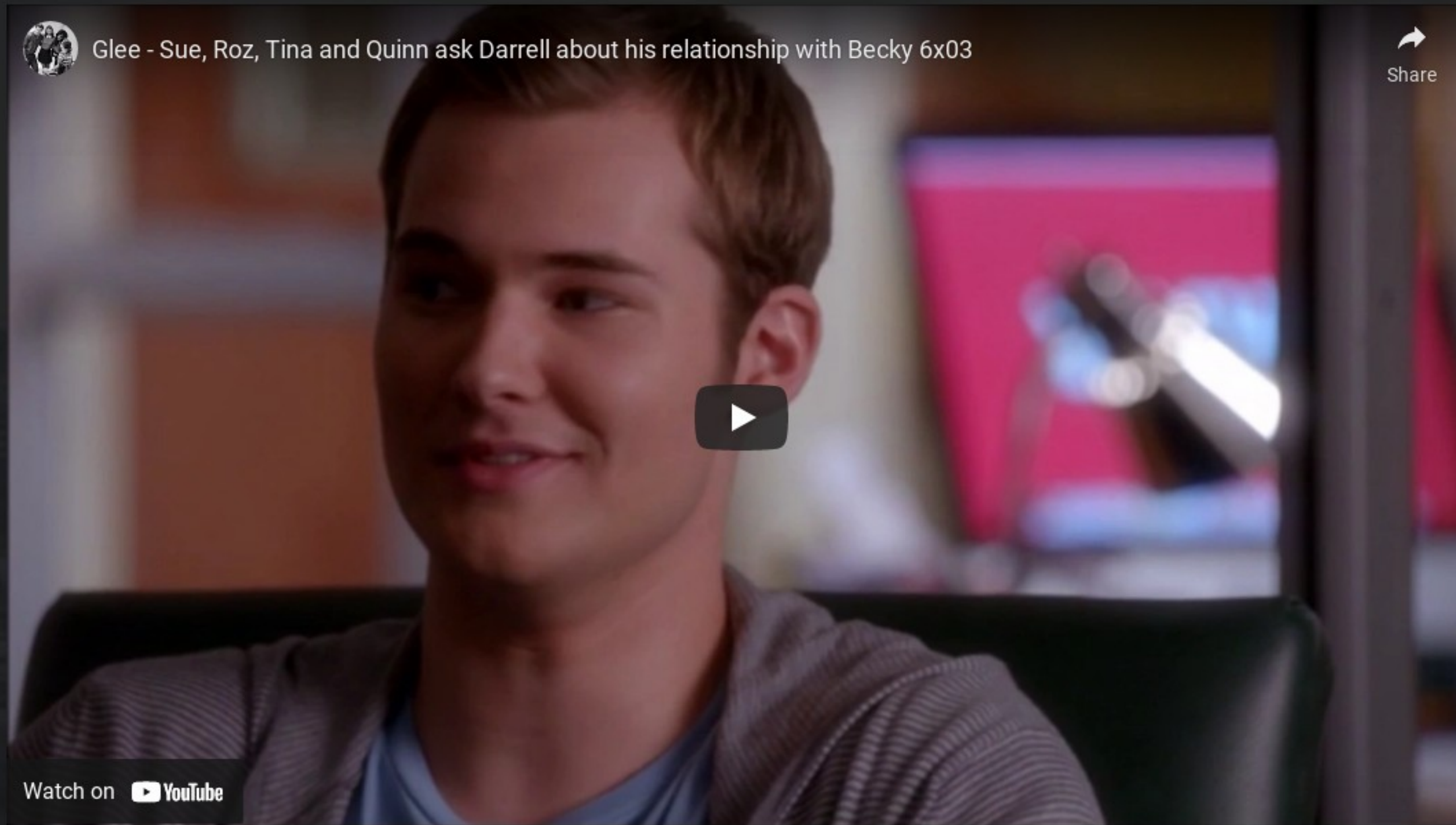
1.6K 255 people are Tweeting about this



# TRUE OR FALSE: PEOPLE WITH DISABILITIES ONLY DATE OTHER PEOPLE WITH DISABILITIES.







# DISABILITY AND DATING: GLEE





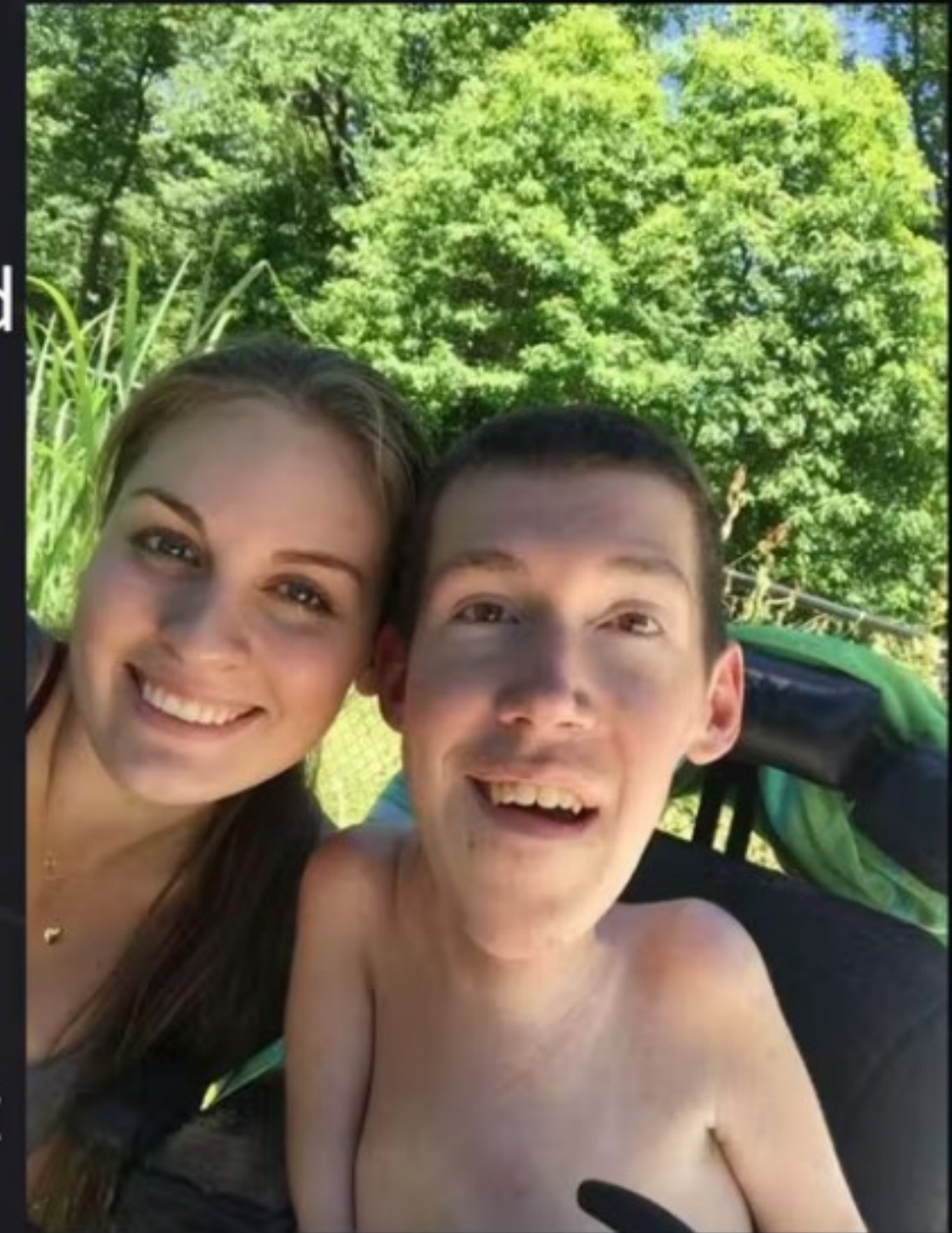
# Shane Burcaw and Hannah Alyward

**As a kid, did you expect to enter an interabled relationship when you grew up?**

I hoped for it, but as a kid, I didn't think about it a whole lot. Society pumped into me the idea that as someone living with a disability, I wasn't really a valuable partner. On some level, I definitely internalized that idea and saw myself as not very valuable. It wasn't until later that I realized how damaging that idea was and could begin looking at myself in a healthier way.

**How much did social expectations of masculinity influence that?**

A ton. We have these really old ideas about what a man needs to be in the relationship. He has to be physically protective and do all the manual labor. It's all, in my opinion, silly. But as a young person I didn't have that awareness that it was silly. I just thought, *Well, I can't hold her hand the normal way so I must not be valuable.*





# How Do These Myths and Facts Impact Perceived Value for Someone with a Disability?

As it relates to:

- (1) Value as a person with a disability?
- (2) Value as a sexual partner?
- (3) Having the same access to education and resources as someone who is not disabled?
- (4) Value as a partner or spouse?
- (5) Value as a parent?



# Vulnerable vs. Uniformed

<u>Perceived as a Vulnerable Population</u>	<u>Perceived as an Uninformed Population</u>
Information is withheld/lack of education	Education and knowledge transfer is prioritized
Higher risk for abuse or assault	Lower risk of abuse or assault because individuals are informed and have practiced important skills related to consent, identifying red flags, and making healthy decisions
Less likely to know their rights	More likely to know their rights
Less likely to know how to self-advocate and do so	More likely to know how to self-advocate, be a self-advocate, and reach out for support
Young adults and adults are infantilized and treated like children (often and particularly if their disability is I/DD)	Age appropriate education and resources are provided based on chronological age. Adapting resources to make them accessible based on disability is step two of this process.
Rights and freedoms are restricted or taken away in the "name of safety"	Safeguards are put in place, with direction from the individual, to ensure rights are intact if assistance or support is needed





# Key Takeaways

**People with disabilities have similar desires, wants, needs, goals, and expectations when it comes to:**

- **Sexuality**
- **Relationships and Friendships**
- **Acceptance**
- **Access to essential education/resources**
- **Future Goals**
- **Decision-Making and Independence**



# What Now?

Identifying the tools needed to create a different narrative surrounding disability.

Identify the urge to gate-keep people with disabilities when it comes to sexual health information.

Attend trainings and professional development ideally led by disabled people .

Determine how to create accessible resources & education for various disability types.

Determine how people with disabilities fit into your communities and organizations. Are they included in sexual health education? Are they served by community organizations? Are they taught about consent?

Learn more about disability history and language. Why may this play into our implicit biases?





# Resources

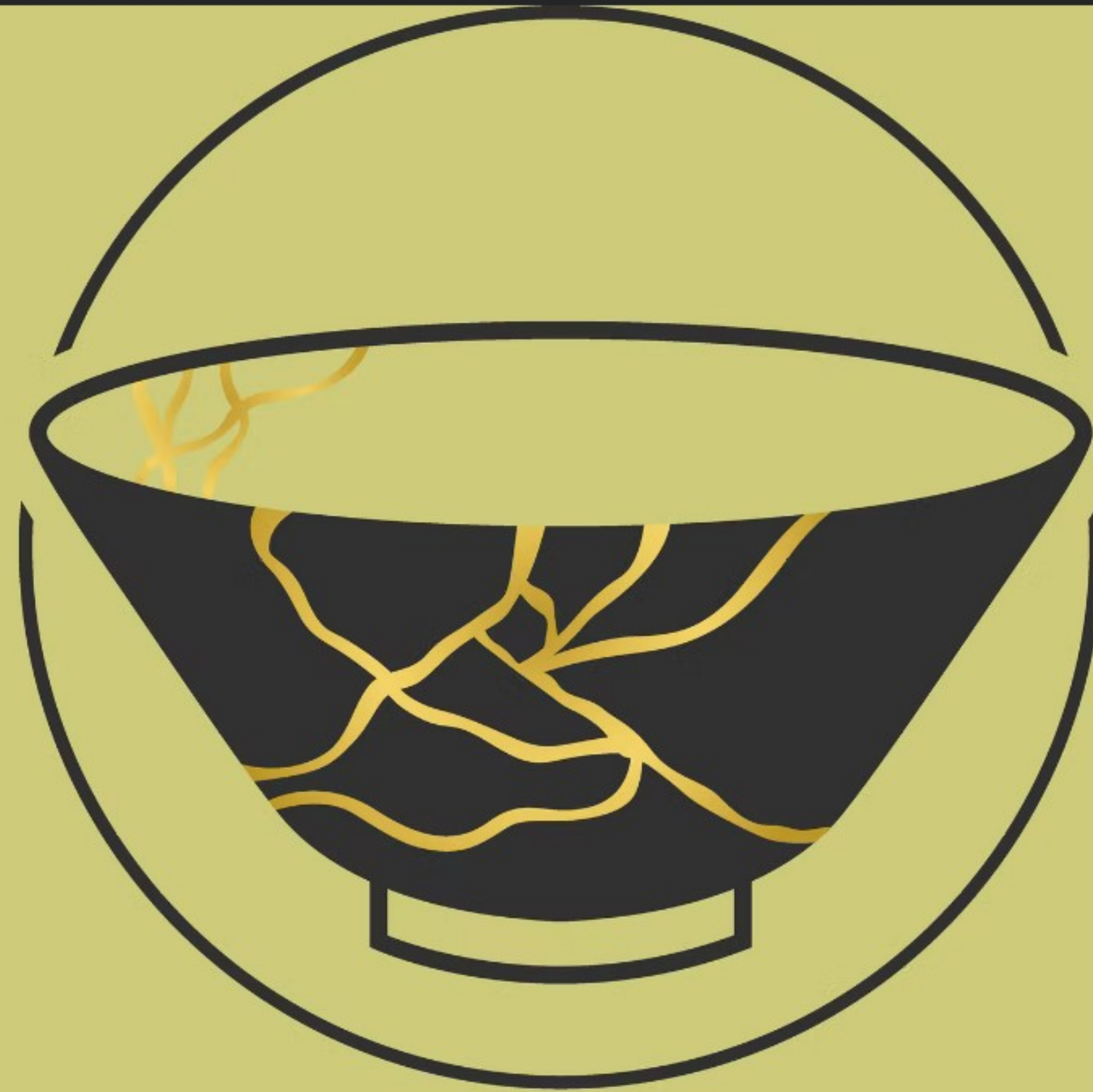
- Americans with Disabilities Act: <http://bit.ly/ADAIntroToDisability>
- Harvard Implicit Bias Study: <http://bit.ly/ImplicitBias101>
- Impact vs. Intention: <http://bit.ly/ImpactVsIntention>
- Disability and the LGBTQ Population: <https://bit.ly/LGBTQandDisability>
- Sexuality and Disability in Media: <https://bit.ly/RepresentationinTVandFilm>
- Article by Shane Burcaw About Interabled Relationships:  
<https://bit.ly/ShaneBurcaw>
- The Harm of Using “Mental Age” Theory: <http://bit.ly/HarmfulMentalAgeTheory>
- Affect the Verb (photos by and of people with disabilities):  
[www.affecttheverb.com](http://www.affecttheverb.com)



# QUESTIONS?

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- ♦ Website: [www.kintsugiconsultingllc.com](http://www.kintsugiconsultingllc.com)





# Kintsugi Consulting, LLC

**THANK YOU FOR PARTICIPATING**

