

a documentary about isolation, art, and transformation after brain injury

# **Who Am I** To Stop It

by Cheryl Green & Cynthia Lopez

# **Discussion Guide**

CLINCIANS, PROVIDERS, ARTISTS, ART THERAPISTS, EDUCATORS, ACCESS COORDINATORS

### WELCOME

Thank you for viewing "Who Am I To Stop It," a documentary on isolation, art, and transformation after brain injury. This guide can support you in discussing the film and topics about living with disability from traumatic brain injury (TBI). Our starting point is a trio of stories from artists with TBI.

"Who Am I To Stop It" is available as an 82-minute film and as three shorts, each under 35 minutes.

#### Our goals:

1. To amplify the art and creativity of people with TBI. Disability art is not inherently sad, special, or inspiring. Whether for social critique or self expression, disability art is art. **Artists with disabilities deserve space to share their own stories from their own perspectives.** 

2. To support mental, physical, and social well-being of communities. Building healthy communities requires addressing stigma, access to resources, racial and gender equity, economic stability, housing, incarceration, violence, mental health, and ableism. And it's important to recognize people have different needs at different life stages and that recovery is more than rehabilitation. **Documentary film is a dynamic way to raise these issues.** 



Dani Sanderson







Kris Haas

## **ABOUT THIS GUIDE**

This Discussion Guide provides provocative and thoughtful questions based on Dani, Brandon, and Kris's stories. We invite you to let their stories open discussion, raise issues, and guide you to new insights and possibilities in how you engage with people with TBI in your work and your communities.

We are guided by the World Health Organization's International Classification of Functioning, Disability, and Health (ICF) and the Social Model of Disability. Both define disability and disablement as the responsibility of the community, not only the individual with impairments.

For each artist, we offer moments from the film and accompanying questions. You may want to also identify other moments that piqued your curiosity or challenged you.

The film and the Discussion Guide are focused on self and community and are not medically-oriented. To learn more about medical facts, statistics, symptoms, and treatment of brain injury, please refer to Brainline.org, Brain Injury Association of America, and United States Brain Injury Alliance.

# PART1: DANI'S STORY

Dani's story is unique in this film because she:

- does not identify as part of the TBI community
- is the only person of color survivor in the film
- has made multiple suicide attempts
- prefers to focus on love and sexuality, not rehab
- self-medicates to deal with isolation, frustration

The film opens with Dani in church with her family. She feels both tremendous love and fear of judgment.

*"If I could ask any freakin' question, it would probably be why me? I've been asking that question for the past five years, and no one can answer it."* 

- How might you bear witness to difficult and uncomfortable conversations with survivors?
- How do you show empathy without rushing to solve problems for others?
- What resources are available to discuss disability and faith?





2 In the Oasis Youth Center library, Dani finds a biography on a Black female athlete who is suddenly hospitalized. Although Dani struggles with reading, she checks out the book.

> "This girl is me on a book, and it is so cool. I don't know if I showed you my book, but I'm doing this too."

- How do you assist people to find culturally relevant role models and peer mentors?
- In what ways might storytelling guide setting therapeutic goals and measuring success?

Dani shows us her typical day: sipping coffee and writing, medicating at the marijuana dispensary, and walking alone.

"I don't know if I should be ashamed of it, but I feel like I fit in when I'm high cuz everyone's talking to me, listening to me."

- What are ways to address isolation and pressure to conform to able-bodied standards?
- How can you encourage the people you work with to trust themselves in choosing what works for them?

# PART 2: BRANDON'S STORY



Brandon's story is unique in this film because he:

- does not focus on limitations from his impairments
- actively explores his relationship to God and faith
- lives in an assisted living facility that provides 24hour support and rehabilitation
- maintains friendships outside of family

Brandon was a Straight A college student. Years after his injury, he re-enrolls and receives an F. He was not aware of accommodations at his private college.

> "That was a wakeup call for me that this is probably not exactly what I'm supposed to be doing right now."

- How might you encourage people to learn about disability rights and practice self-advocacy?
- Where do you find information on accommodations and learning supports?

In an interview, Brandon talks about feeling his semi-paralyzed face discredits him as a possible leader in his church community.

"I became a Worship Pastor for the church at the time. I can't play that role anymore."

- What tools do you have to address stigma and internalized ableism?
- How might you support people in a process of finding a new passion, career, volunteer opportunity, or contribution to society?



Brandon talks about his TBI at Refuge, his church's peer support meeting. His faith and spiritual devotion help him move forward, free from anger about his situation.

*"It just seemed like the right thing for me to do, is to forgive the guy that did this horrible thing."* 

- What community supports are available in your area that provide space for survivors to be heard and move forward?
- How might spirituality, religion, and deep reflection play a role in healing that is different from physical and cognitive therapy?

# PART 3: KRIS'S STORY

Kris's story is unique in this film because she:

- is estranged from her family
- rarely leaves home
- can earn money as an artist at times
- lives in subsidized housing and in poverty
- is in middle age and had a career

Kris gets an eviction notice. She talks to a gallery owner about losing her apartment while her \$5,000 paintings hang on the wall.

*"I was expecting a notice Tuesday morning that the sheriff was gonna be coming."* 



- How might you support people to address their basic needs and social needs?
- What resources are you aware of that provide financial or other types of support for people with disabilities in poverty?



2 Kris has attempted suicide in response to losing her career, identity, and the home she owned.

*"If I had a brain injury, but I didn't have the art, I probably would've been practically suicidal, even more so."* 

- How do you tailor your work with people of different ages and life stages to meet their differing needs?
- What might be different about adjusting to acquired disability mid-career versus acquiring disability as a young person?

With a history of mental illness and mild TBI, Kris's family doubts her impairments are real, and she has been denied social security disability benefits multiple times. In an interview, she talks about her ongoing struggle with finding people who validate her situation.

"I look normal, but you hang with me one day. You think I'd go to these lengths to make this up, when I could easily be working two jobs if I was normal?"

- How might you address the multi-dimensional needs of someone with several co-occurring health issues, including mental health concerns?
- How do you validate others' experiences and perspectives?

# PART 4: THE WORLD HEALTH ORGANIZATION AND THE SOCIAL MODEL OF DISABILITY

#### World Health Organization's International Classification of Functioning, Disability, & Health (ICF)

Disability is a complex relationship of limitations from impairment and limitations from society's barriers. Barriers are structural (lack of ramps, no quiet space to rest) and attitudinal (bullying, refusing accommodations).

Experience of health, wellness, or disability is tied to a person's life context, including education level, income, previous injury, coping skills, religion, race, ethnicity, and cultural competence of providers.

#### Essential questions in working with people with disabilities

- How might you get to know your clients' life contexts?
- How might you acknowledge when your life context is different from theirs?
- How might you structure activities that speak to someone's cultural values and personal interests even if those are very different from yours?

#### Health is a state of physical, psychological, and social well-being

• If you treat a physical injury or mental health concern, how might you also address the consequences of impairment on the individual and their community?

#### How this relates to brain injury

Testing and treatment in a controlled setting may show someone's capacities, but it may not reveal how they perform in complicated, noisy, unpredictable settings found in real life.

- What can you learn about a TBI survivor's performance in their everyday environment?
- How might you create therapeutic experiences that feel relevant and motivating to your clients?

#### The Social Model of Disability

The Social Model challenges the Medical Model of illness and injury by claiming that many difficulties arise from an inaccessible society, not just an impairment. The Social Model reminds us to address society's barriers in addition to, or in place of, neurological and physical recovery.

#### Using the Social Model in medicine and rehabilitation is complicated

Insurance billing, time constraints, variable evidence base, and other factors contribute.

• Yet how might you regularly account for the wishes and preferences of the person with TBI?

#### Not all TBI survivors are interested in or able to meet all recovery goals

• How might you work on realistic recovery goals and also promote strategies to educate nondisabled community members to be more accommodating?

A standalone version of this page can be found at newday.com/film/who-am-i-stop-it.

# **PART 5: RESOURCES**

#### Suicide

For Clinicians: <u>sprc.org/sites/default/files/migrate/library/TBI\_Suicide.pdf</u> Brainline.org: <u>brainline.org/content/2011/05/depression-after-brain-injury\_pageall.html</u> National Suicide Prevention Lifeline: 1-800-273-8255; <u>suicidepreventionlifeline.org</u>

#### **Domestic Violence**

For Clinicians: <u>doj.state.or.us/victims/pdf/traumatic\_brain\_injury\_and\_domestic\_violence.pdf</u> Brainline.org: <u>https://tinyurl.com/yy3zhm7h</u> National Domestic Violence Hotline: 1–800–799–7233; TTY 1–800–787–3224; <u>thehotline.org</u>

#### **Cultural and Ethnic Diversity**

Villisa Thompson's Ramp Your Voice: <u>rampyourvoice.com</u> Disability Visibility Project and #GetWokeADA26: <u>disabilityvisibilityproject.com</u>

#### **Disability Arts**

Unmasking Brain Injury: <u>unmaskingbraininjury.org</u> Disability Arts International: <u>disabilityartsinternational.org</u>

#### **Documentary Films**

When Billy Broke His Head and Other Tales of Wonder: <u>kartemquin.com</u> Brain Injury Dialogues: <u>braininjurydialogues.org</u> Marwencol: <u>marwencol.com</u>

#### **Multi-topic TBI and Disability Resources**

Life Skills Village: lifeskillsvillage.com/resource-links.html Changed Lives, New Journeys: changedlivesnewjourneys.com Bridging the Gap: tbibridge.org/index.html

#### Neurodiversity

NOS Magazine news and commentary: **nosmag.org** Archived web list of resources and articles: **neurodiversity.com** 

#### **Religion and Faith and Disability**

Colllaborative on Faith & Disabilities: <u>faithanddisability.org</u> Disability and Jewish Acceptance ELI Talks: <u>https://youtu.be/COJvIrVoD-4</u>

#### **Storytelling Projects and Blogs**

Headway London East Who Are You Now?: <u>whoareyounow.org</u> Krempels Center Oral History Project on YouTube: <u>tinyurl.com/l79y8ws</u> Lash & Associates Training/Publishing Blog: <u>lapublishing.com/blog</u>

#### **Veterans and Civilians and Homelessness**

Long March Home: longmarchhome.org/tbi\_homelessness.html Street Roots street newspaper series on TBI: http://tinyurl.com/pkh2w3u

# PART 6: WHERE ARE THEY NOW?

We filmed Who Am I To Stop It from 2012 to 2014. A documentary freezes people in time, and the most common question we get after screenings is, "Where are they now?" Here are updates from Fall, 2019.

Shortly after her eviction, Kris got stable, supportive housing and continues to paint. Dani met a wonderful woman, and they have been together since 2017. She also took one community college class and got her first job at DSW. Brandon left the church and ended his practice as a Christian. He moved out of KMS and into his own apartment downtown.

Because Brandon's life changed so radically, we went back and filmed him again in 2017. The full film is available broken into three short films. Brandon's is the only one with new footage due to the time and cost it would take to completely remake and update the film.

# PART 7: ABOUT THE FILMMAKERS

Cynthia Lopez MA, MUS and Cheryl Green, MFA, MS met at Portland State University when Cynthia was Cheryl's supervisor on a research study about adult literacy practices. After Cheryl acquired disabilities from TBI, Cynthia filmed, edited, and produced Cheryl's two short films, "Cooking With Brain Injury" and "Friending With Brain Injury." They produced and directed "Who Am I To Stop It" together.

Cynthia is dedicated to collecting, editing, documenting, and preserving narratives about people and places. This has taken several forms throughout her career, from qualitative research to documentary filmmaking to working on oral history projects that increase access to the history and experiences of people in the Pacific Northwest, with a particular focus on amplifying marginalized voices.

Cheryl is a multi-media digital artist, captioner, audio describer, 2017 AIR New Voices Scholar, and member-owner at New Day Films. She brings her lived experience with multiple invisible disabilities to creating media that explores politically- and culturally-engaged stories from cross-disability communities. Her audio and written blog, transcribed podcast, and films are at <u>WhoAmIToStoplt.com</u>.



Cynthia on location to film Kris.



Cheryl and Kris enjoying a day of filming.

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