# VISUALIZING INVISIBILITY

Taree Vargas, MA Anthropology

HXDI
Department
of Design
CSULB

Master of Arts
Human Experience Design Interactions

# PROJECT START-UP

SELECTIVE MUTISM

INVISIBILE ILLNESS




Literature from sources from Hurssel to Marchand & Merleau-Ponty (we express phenomena of consciousness (such as learning and religion) through the body (embodiment)) to Pink's sensory ethnography center outward expression of human experience, but much of experience is invisible

PHENOMENOLOGY

Embodied Subjectivity

SENSORY ETHNOGRAPHY



Edmund Husserl



Maurice Merleau-Ponty



Sarah Pink

METAPHORICAL

LITERAL

Is this experience widely understood?

illnesses without obvious external expressions

ISSUE
people are not always believed that they are ill by medical professionals or others in positions to accommodate or in some other way help them.

Are there narratives about this experience in popular dialouges?

If these conditions are met, we have metaphorical VISIBILITY of an issue



"If its mentionable, its manageable."

VISIBILITY

ACTIONABLE

What purpose does metaphorical VISIBILITY serve?

NORMALIZATION

Improved quality of life

## Summary

In addition to a thesis paper on the complex of issues facing people with invisible illnesses situating these experiences within anthropological theoretical contexts, this project seeks to work with between one and five people experiencing invisible illnesses to create immersive virtual reality films that evoke their experiences for audiences with the goal of increasing understanding thereby normalizing those illnesses that may be stigmatized due to lack of visibility.

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2020-2021 Cohort X2(+/-)

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## Statistical Data:



www.understood.org

**Understanding invisible disabilities in the workplace**

Learn about invisible disabilities in the worklplace and how you can better support your employees with challenges like ADHD, mental health issues, and more.

Invisible illness or disability refers to a range of conditions including certain mental and physical illnesses the symptoms of which are not prominently visible to others.

"It is estimated that **10%** of people in the U.S. have a medical condition which could be considered a type of invisible disability. "

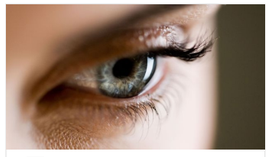


www.disabled-world.com

**Invisible Disabilities: List and General Information**

Information on invisible disability, disabilities that are not immediately apparent, includes a list of hidden disability conditions.

"**96%** of people with chronic medical conditions live with an illness that is invisible. "

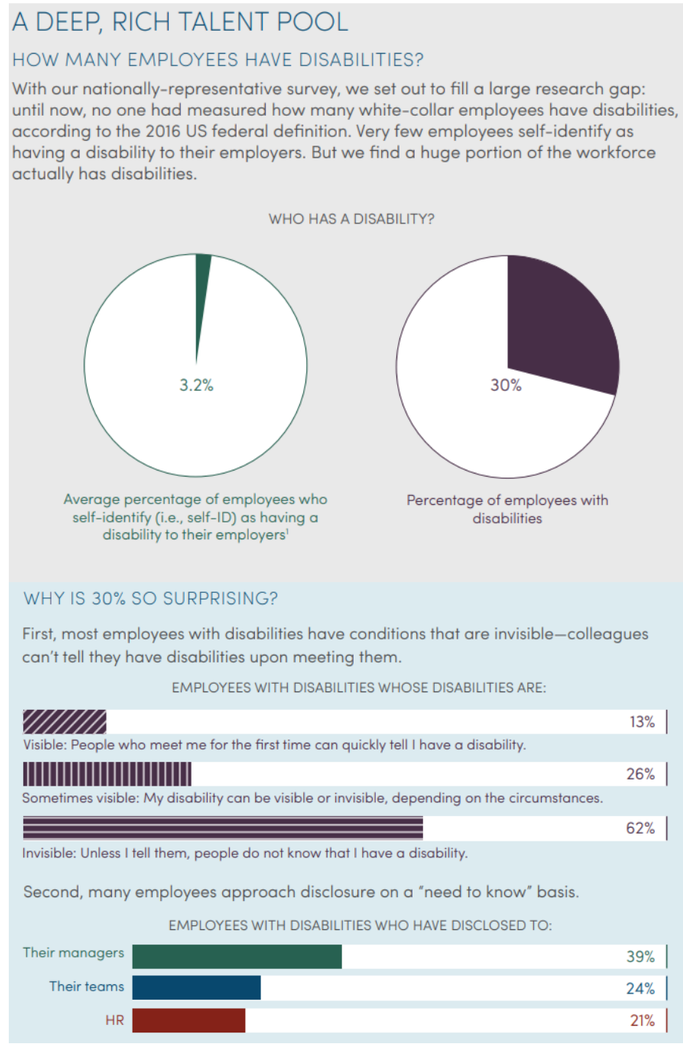


www.bbc.com

**The hidden challenges of invisible disabilities**

Millions of people work with disabilities they rarely talk about, but greater awareness can help both employers and employees, writes Jessica Holland

"A 2011 Canadian survey found that **88%** of people with invisible disabilities had a negative view of disclosing their disability."




## Qualitative Data:



www.goodreads.com

**The First Step**

A collection of thoughts on surviving: surviving the world, surviving mental illness, and surviving the thoughts in your own head. It i...

"People assume you aren't sick
unless they see the sickness on your skin
like scars forming a map of all the ways you're hurting."
**Emm Roy, Author of The First Step, Mental illness sufferer**

"If I say, "I have Chronic Fatigue Syndrome," I'm likely to be discredited as a witness to my own condition. I've had doctors tell me there's no such thing as Chronic Fatigue Syndrome. One doctor said: "Just drink some coffee."
**Toni Bernhard**

"When you have an invisible disease, your sickness isn't your biggest problem. What you end up battling more than anything else, every single day, is other people."
**Heidi Cullinan**

"This invisibility can reduce the social support received from network members and adversely affect the quality of life."

"Respondents felt that their [illnesses were] invisible to social ties and to medical professionals. In addition, treatment and organizational factors in health care contributed to the sense of inadequate care. Finally, validation was derived from informational and emotional support from both support groups, and from some medical professionals."

link.springer.com

**Living with invisible illness: social support experiences of individuals with systemic lupus erythematosus**

Purpose Because symptoms are not immediately visible to others, systemic lupus erythematosus (SLE) is often considered an invisible illness. This invisibility can reduce the social support received from network members and adversely affect the quality o...




www.fishinsurance.co.uk

**Survey reveals prejudice towards people with “invisible” disabilities - The Hub**

The extent of negative public perceptions towards people with so-called “invisible” disabilities has been highlighted in a study commissioned by Fish Insurance.

“In a national survey, 39 per cent of people said someone who displayed a valid Blue Badge but did not appear to have difficulty walking should not be entitled to park in a disabled parking bay.

A further 18 per cent thought even blue-badge holders who displayed some difficulty walking, such as those with a limp or prosthetic limb, should not be allowed to use disabled parking facilities.”

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"Millennials are the first generation whose education largely began after the passage of the Americans with Disabilities Act in 1990.”

“...increasing diagnosis rates of certain conditions--mental health conditions like depression and anxiety, cognitive conditions like dyslexia, developmental differences like autism, and other forms of neurodiversity--may contribute to a higher proportion of disability in the Millennial white-collar workforce. Millennials are also more likely than Xers or Boomers to report that they have a mental health condition: Forty-four percent of Millennials, compared to 37% of Gen Xers and 25% of Boomers.”



www.inc.com

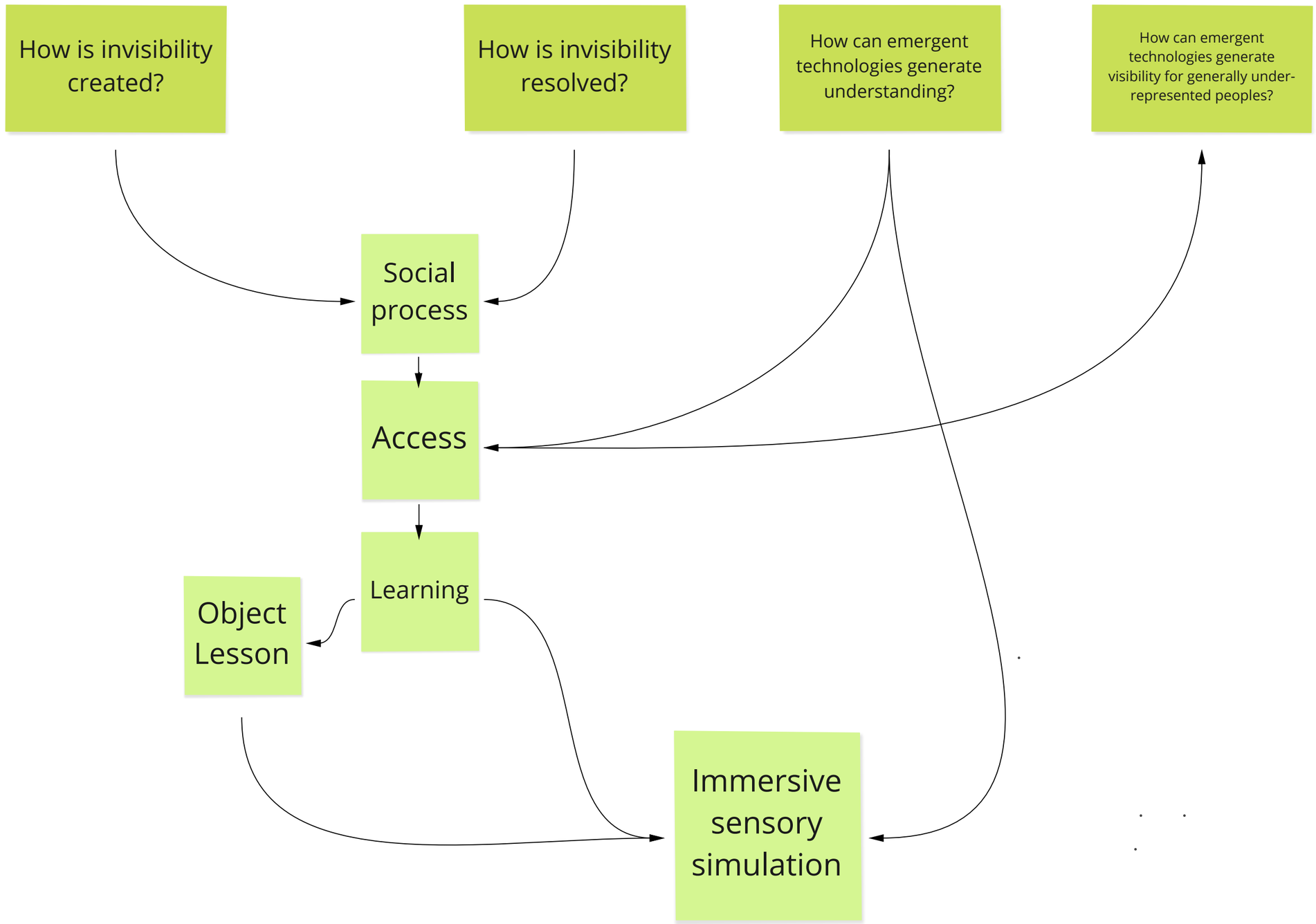
**Millennials with Disabilities: A Large, Invisible Talent Cohort with Innovative Potential**

Two phenomena contribute to the high number of Millennials with disabilities.

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Working from disability studies specialist Lennard J. Davis's Post-Modern Disability Theory stating "that disability is an unstable category in need of reconceptualization [and] the revision of the category to include every "body" regardless of its current status as disabled or not,” Disjuncture theory holds that disability is located at the intersection of bodies and environments, meaning that defining disability is context dependent and therefor malleable.




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embodiedlabs.com

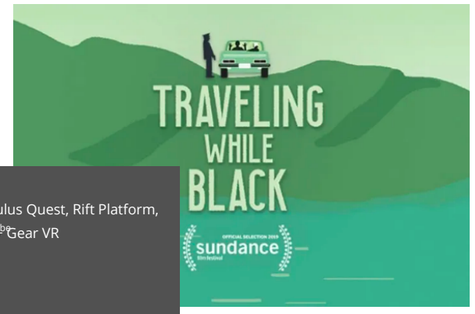
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The immersive training platform for companies committed to providing excellent care and service for the aging population.

www.sciencedir...

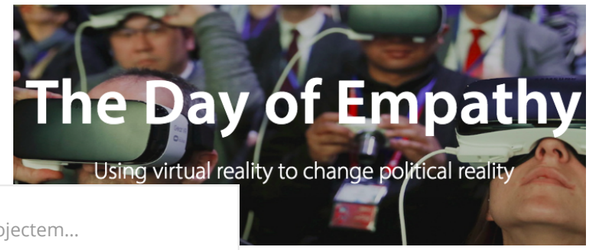
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The theory of psychological proximity implies that individuals should empathize with others more the closer their own experience is to that of the tar...




Traveling While Black | Oculus Quest, Rift Platform, Oculus Go + Gear VR
YouTube









www.projectem...

**Project Empathy**

A virtual reality film series that shows us the world through the eyes of another. See what I see.

"Taking the perspective of others in VR produces more empathy and prosocial behaviors in people immediately after going through the experience and over time in comparison to just imagining what it would be like to be in someone else's shoes,"



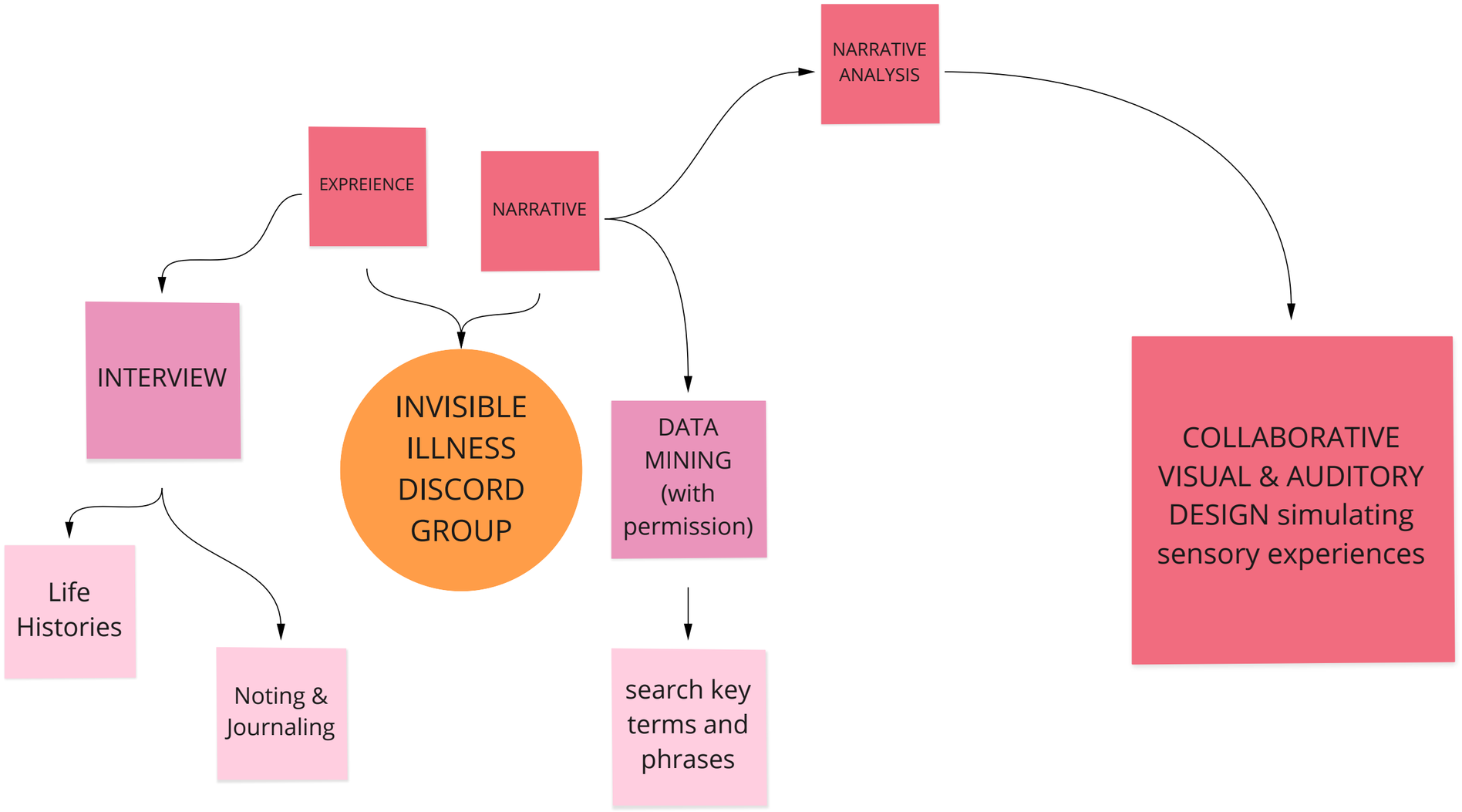
news.stanford.edu

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Stanford researchers found that people who underwent a virtual reality experience, called "Becoming Homeless," were more empathetic toward the homeless.

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EXPREIENCE
NARRATIVE
NARRATIVE ANALYSIS
INTERVIEW
INVISIBLE ILLNESS DISCORD GROUP
DATA MINING (with permission)
COLLABORATIVE VISUAL & AUDITORY DESIGN simulating sensory experiences
Life Histories
Noting & Journaling
search key terms and phrases



Insta360 Pro



Insta360 EVO

Premiere Pro



Immersive Theater





YouTube/
Google
Cardboard

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# Phase 04 - **DELIVER & MEASURE**

CONTRIBUTOR CONTROL

Implement

Friends, family members & coworkers

Organizations like Embodied Labs




High Schools- College & Universities

National Diversity Council




Feedback

CONTRIBUTOR SURVEY

USER SURVEY

MEASURE REACH

MEASURE ACTION

Define Value Created

A full program evaluation will be required to measure the success of this project according to several key markers: the personal satisfaction of collaborators, representativeness, to usability and resulting pro-social behaviors such as participating in calls to action.

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# VISUALIZING INVISIBILITY MEDIA & TOOLS

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# PURPOSE

Work with people with invisible illnesses to create opportunities to emplace audiences within the embodied experience of invisible illness generating greater visibility and understanding.

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# PAST ITERATION

A traditional format film using impressionistic visual and auditory techniques to illustrate a life history of anxiety.




https://player.vimeo.com/video/294706178?title=0&byline=0&portrait=0&speed=0&badge=0&autopause=0&player_id=0&app_id=58479

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# IMMERSIVE PROJECTS THAT CENTER HUMAN NARRATIVES EVOKE EMPATHY

+

# EMPATHY HELPS GENERATE PRO-SOCIAL BEHAVIORS

https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0204494

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# HOW CAN WE MAKE INVISIBLE ILLNESSES VISIBLE TO OTHERS?

# SIMULATING EMBODIED ILLNESS EXPERIENCES

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# GENERATE IMMERSIVE ENVIRONMENTS

- 6 cameras
- 5k mode to stitch video internally
- 8k video for high resolution (video translates well in 3D cinema space)
- 4 microphones for immersive sound



Work with collaborators to define immersive environments either in real, virtual, or mixed spaces

Insta360 Pro



## Insta360 EVO



- Dynamic view of 360 space or Stereoscopic mode
- FlowState Stabilization
- Stereo Audio



Film from a first person perspective to help viewers emplace themselves within the space of the narrator.

# CHANGE VIEWER'S PERSPECTIVES

https://www.insta360.com/?gclid=CjwKCAjw6fCCBhBNEiwAem5SD6ijiZWQ3vMzgSGvAk8h7YgvAWEyQXC2KO0DjIJ4uDNDNNmt3rfRQxoCGU8QAvD_BwE

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Phase 03 - **DEVELOP & IMPLEMENT** Technology




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# ALTER REAL SPACE TO QUESTION NORMATIVITY

- Works with a variety of VR headsets
- A variety of colors and textures
- Immersive space in which to create and view

https://www.vrfocus.com/2021/01/google-tilt-brush-now-open-source-creators-instantly-set-to-work/



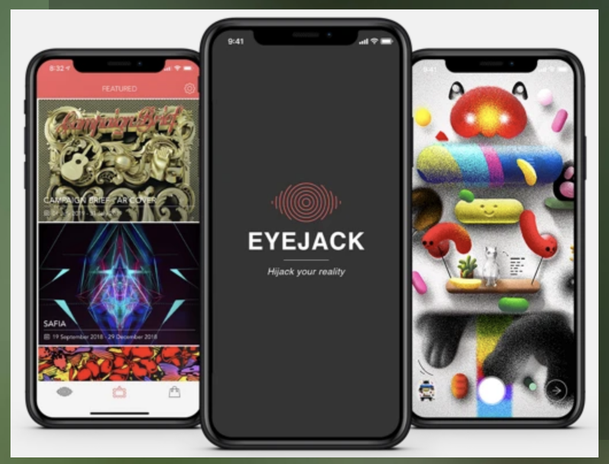

Work with collaborators create evocative impressionistic visuals that illustrate their narratives.



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https://eyejackapp.com/




- Any Image works as a visual key to open a dynamic visual experience
- Viewers do not need the app to view the animation
- Potential to be layered into a project designed for a 3D cinema space.

Work with collaborators to create dynamic visual representations that evoke their embodied experience

**HELP VIEWER'S UNDERSTAND NEW PERSPECTIVES**

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# CREATE A VISUAL NARRATIVE

- Combine visual and audio elements to develop a cohesive narrative
- Effects to help refine raw footage
- Ability to construct 360 immersive environments

Work with collaborators to build their narratives into evocative immersive visual and auditory experiences.





- Immersive viewing
- Opportunity for interaction
- Collective meaning making
- 360 sound

Allow viewers to feel immersed in the perspective of storytellers and gain new insights into their embodied experience.

# ENGAGE VIEWERS IN COLLECTIVE MEANING MAKING

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# MAKE IT ACCESSIBLE

- Dynamic view of 360 space
- Accessible price point

Offer collaborators a stock of google cardboard headsets to disperse among those they want to engage with their immersive projects.



# RECALLING THAT:

**IMMERSIVE PROJECTS THAT CENTER HUMAN NARRATIVES EVOKE EMPATHY**

+

**EMPATHY HELPS GENERATE PRO-SOCIAL BEHAVIORS**

https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0204494

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# FURTHER QUESTIONS INCLUDE:

**Does interactivity increase:**
**+ understanding**
**+ empathy**
**+ contribution?**

**How to make it interactive?**

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# VISUALIZING INVISIBILITY *TECHNOLOGY*

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# HOW CAN WE MAKE INVISIBLE ILLNESSES VISIBLE TO OTHERS?

# SIMULATING EMBODIED ILLNESS EXPERIENCES

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# PURPOSE

Leverage a flexible set of technologies that help express participants' diverse experiences and ultimately create visual projects that emplace audiences in the first person perspectives and embodied experiences of those with invisible illnesses to evoke understanding and empathy...

# IMMERSIVE PROJECTS THAT CENTER HUMAN NARRATIVES EVOKE EMPATHY

+

# EMPATHY HELPS GENERATE PRO-SOCIAL BEHAVIORS

https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0204494

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# TECH PHASE 01-A

## GENERATE IMMERSIVE ENVIRONMENTS

- 6 cameras
- 5k mode to stitch video internally
- 8k video for high resolution (video translates well in 3D cinema space)
- 4 microphones for immersive sound



Work with collaborators to define "real" immersive environments.

Insta360 Pro



# TECH PHASE 01-A

Ø Ensure formatting is in EXFAT

Ø Select stitching calibration after camera turned on > distance 2m from camera with no obstructions > Press “power” button in app and camera will calibrate based on surrounding scene

Ø Use app on mobile phone to control video recording within click on confirmation button to begin recording, click on it again to end recording.

## Insta360 Pro Workflow

Adapted from: https://onlinemanual.insta360.com/pro1/en-us/basic/prepare/4

# AR

Augmented Reality

Work with collaborators create evocative impressionistic visuals that illustrate their narratives.

**ALTER REAL SPACE TO QUESTION NORMATIVITY**

**HELP VIEWER'S UNDERSTAND NEW PERSPECTIVES**

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# TECH PHASE 01-B

## CREATE IMPRESSIONISTIC VISUAL ELEMENTS

Work with collaborators to create evocative impressionistic visuals that further illustrate their narratives. *Collaborators have primary control over this stage of the process as they control the tool.*

https://www.vrfocus.com/2021/01/google-tilt-brush-now-open-source-creators-instantly-set-to-work/




- Works with a variety of VR headsets
- A variety of colors and textures
- Immersive space in which to create and view
- May build environments from scratch
- Ease of use

Tilt Brush



# TECH PHASE 01-B

- Ø Record +/- 5 sec. of video of Tilt Brush object
- Ø Export
- Ø Close Tilt Brush
- Ø Go to Downloads> Tiltbrush> Videos> Select “Bat” file
- Ø Select “6”- omnidirectional Stereo 360, 4k 30 FPS
- Ø Wait for video to render
- Ø Go to Documents> Tiltbrush> VRVideos> Open folder
- Ø Select File (equirectangular format)
- Ø Crop to 2:1 ratio
- Ø Ensure image is fitted to edges to avoid stitch lines
- Ø Export as .mp4

## Export Tilt Brush Object Workflow

Adapted from: https://www.youtube.com/watch?v=n31CtycR3KI

# TECH **PHASE 02**

## CREATE A VISUAL NARRATIVE

- Combine visual and audio elements to develop a cohesive narrative
- Effects to help refine raw footage
- Ability to construct 360 immersive environments

Build narratives, other audio and visual elements into into evocative immersive experiences.

Premiere Pro



# TECH PHASE 02

- Ø Select VR videos > Convert in VR180 Creator first.
- Ø In Premiere, Click Import.
- Ø Drag and drop clip into "Timeline" window.
- Ø To set VR properties, click Sequence > Sequence settings.
- Ø Under "VR properties," click down arrow > Select “Equirectangular.”
- Ø Under "VR properties," select Stereoscopic - over/under.
- Ø Change "Horizontal captured view" to 180 > Click OK.
- Ø Drag other clips into sequence.
- Ø Add titles, graphics, and effects
- Ø Create sequence with 1 x 1 aspect ratio.
- Ø Select cropped 180˚sequence.
- Ø In Project pane, click sequence to export.
- Ø Click File > Export > Media.
- Ø Select Format: H.264.
- Ø In Video pane, under "Basic video settings," enter resolution.
- Ø Click Encoding settings > Profile > Select High.
- Ø Click Bitrate settings > Bitrate encoding > Select VBR, 1 Pass.
- Ø Change target/max bitrates to match resolution.
- Ø Under "VR video," make sure Video is VR is checked.
- Ø Select > Frame layout: Stereoscopic over/under > Horizontal field of view: 180 > Vertical field of view: 180
- Ø Under "Source scaling," click Stretch to fill.
- Ø Type a name for your file.
- Ø Click Export.

## Edit VR film in Premiere Workflow

Adapted from: https://support.google.com/vr180/answer/9047774?hl=en

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# OTHER TOOLS UNDER CONSIDERATION

Studio 3D Max

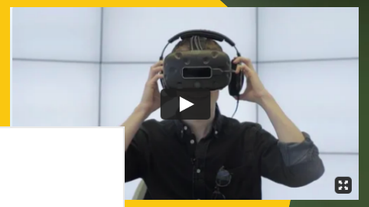



A greater need for ease of use by research participants with varying levels of technological skills is required for this project.

Both useful for creating evocative impressionistic visuals that illustrate narratives through dynamic storytelling.

Twinmotion

# TECH CASE STUDIES



embodiedlabs.com

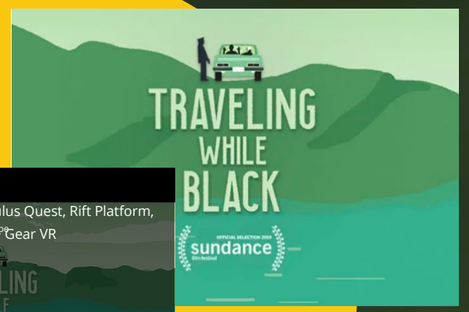
**Embodied Labs - Immersive Training Platform**

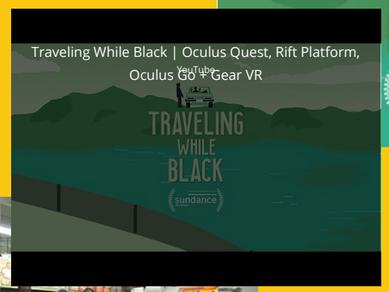
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# DATA OF THE ISSUE

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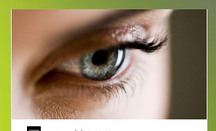
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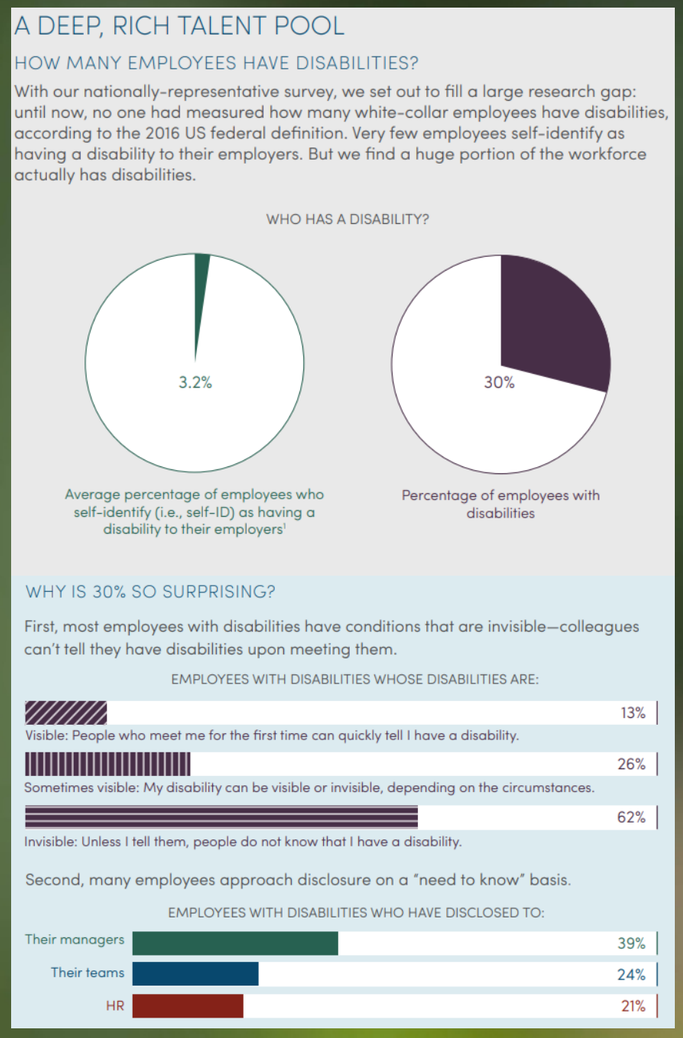


www.bbc.com

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"A 2011 Canadian survey found that **88%** of people with invisible disabilities had a negative view of disclosing their disability."




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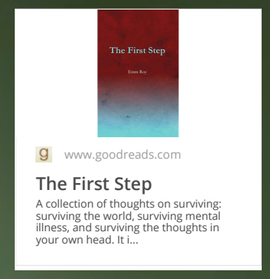
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link.springer.com

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www.goodreads.com

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A collection of thoughts on surviving: surviving the world, surviving mental illness, and surviving the thoughts in your own head. It i...

"People assume you aren't sick
unless they see the sickness on your skin
like scars forming a map of all the ways you're hurting."
**Emm Roy, Author of The First Step, Mental illness sufferer**

"If I say, "I have Chronic Fatigue Syndrome," I'm likely to be discredited as a witness to my own condition. I've had doctors tell me there's no such thing as Chronic Fatigue Syndrome. One doctor said: "Just drink some coffee."
**Toni Bernhard**

"When you have an invisible disease, your sickness isn't your biggest problem. What you end up battling more than anything else, every single day, is other people."
**Heidi Cullinan**

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# Work Flow

This work centers research collaborators from driving conversation in interviews to creating impressionistic details

**Work with collaborators to define immersive environments either in real, virtual, or mixed spaces**

## VR

Audio recording with **Sennheiser AMBEO 3D Virtual Reality Mic**

INPUT

Import audio & footage into **Premiere** to edit all elements into a cohesive short VR film.

**Innovation Space**

**Insta360 EVO + Insta360 Pro** to generate "real" footage

INPUT

## AR

Work with collaborators to generate impressionistic visual elements that correspond to their embodied experience using **Tilt Brush**

INPUT

**Oculus Quest**

INPUT

INPUT

Export in appropriate formats for housing across multiple platforms.

INPUT

**Youtube**

# MVP Work Flow

**This version of the work centers the researcher's impressionistic interpretation of the qualia of invisible illnesses**

## VR

***Use qualitative data*** **to define immersive environments either in real, virtual, or mixed spaces**

Audio recording with **Sennheiser AMBEO 3D Virtual Reality Mic**

**Insta360 Pro** to generate "real" footage

Use **Tilt Brush** to generate impressionistic visual elements that correspond to ***data representing*** embodied experience

## AR

**Oculus Quest**

Import audio & footage into **Premiere** to edit all elements into a cohesive short VR film.

Export in appropriate formats for housing across two platforms.

**Youtube**

INPUT

INPUT

INPUT

INPUT

INPUT

# THANK YOU.

*Please see work posted to public platform at:*

http://tareevargas.com/hxdi-tech-presentation/

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