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Advancing Digital Health Humanities Institute

Title

Exploring Frameworks of Neurodiversity in the Digital Era

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FLIPPING THE SCRIPT

Neurodivergent Narratives

By Esperanza Padilla



Positionality Statement

- Autistic & ADHD (“late diagnosis”)
 - Latina/First gen college student
- 4th year PhD Candidate in Sociology
- Trained Digital Storytelling Facilitator

Background & Motivation



- **Western society neurodivergence** is largely understood thru **the medical model:** see conditions (e.g., Autism, ADHD) as pathological states in need of “cure”
- [Biomedical] “**master narratives**” limits what research questions we ask and how knowledge is created (shuster & Westbrook 2022)
- **Overlook the embodied experiences of neurodivergent (ND) people**
 - → devalues ND people as knowledge experts

Background & Motivation



- Nonnormative narratives (Scully 2008) conceptualize disability/neurodiversity as forms of embodiment that are culturally and collectively crafted and challenge master narratives
- Participatory arts - based methods (e.g.digital storytelling) can disrupt master narratives;
- Promote inclusion and agency among community members typically excluded from the research process (Mykitiuk 2015; Rice & Mündel 2019; Sikapa et al. 2024).



Research AIMS

1

Investigate whether and how online social interaction serves as sites for the collective construction of alternative narratives, scripts, and shared cultures of joy and affirmation about neurodivergence.

2

Explore how ND people receive, interpret, and respond to these flipped narratives and scripts, and whether and how they influence their understandings and everyday experiences of neurodivergence

3

Reveal how ND people co - create knowledge through the production of digital counter stories and a community developed digital archive

METHODS OVERVIEW



- ★ Digital ethnography of posts on Tumblr hashtags (e.g. neurodiver /gence/ent, Autism, ADHD)
- ★ Longitudinal In - depth Interviews with ND adults (e.g., Autism, ADHD) who use online spaces (N = 35)
- ★ Digital Storytelling & Co - Production of Archive
 - *Consist of 10 “research collaborators”* who will create a digital story
 - Help co-curate and steward digital archive

Methods: digital Storytelling

- ★ **Research collaborators** will be selected based on the following criteria:
(a) participant interest in volunteering as a research collaborator, (b) any past experience with art or creative methods (e.g. writing, drawing, or video editing), and (c) participant's background as belonging to one or more marginalized group (e.g., Queer, BIPOC, Native American, or Non-Speaking Autistic).
- ★ **Each will co - produce a digital counter story** based off a moment they identify in their **initial interview**
- ★ **Follow - up interview:** we will identify a moment from initial interview or another story they wish to tell ; schedule facilitation meetings

Example of a Digital Story

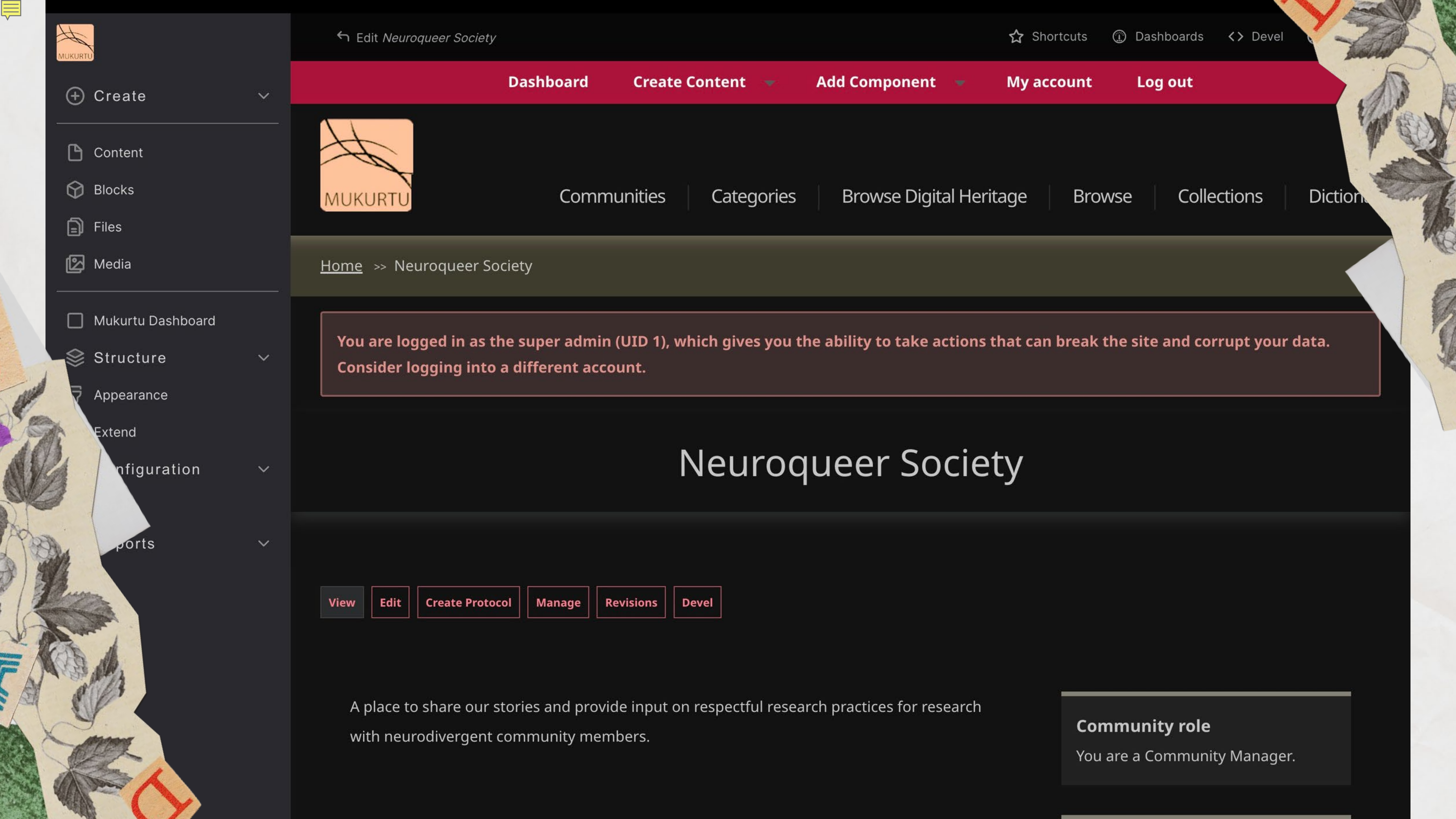


<https://youtu.be/K8TbkWKXuic?si=kTcPul2ZNx7Gz0lh>

The background of the slide is a collage of crumpled, light-colored paper. Overlaid on this are several botanical illustrations, likely from a vintage book or paper, showing various leaves and small, cone-like plant structures. The illustrations are in shades of brown, green, and red. In the top left corner, there is a small yellow speech bubble icon. The title 'Digital Archiving with Mukurtu' is written in a large, purple, serif font, with 'Mukurtu' on a second line.

Digital Archiving with Mukurtu

- **Why Mukurtu?** → affords accessibility features that also allow for best research practices with ND community members, including tiered access
- **1st tier: designed for ND community members**, will be closed access and contain those digital counter stories that their creators wish not to be shared with the public, as well as reflective diary entries and memos.
- **2nd tier: accessible to non - ND researchers and the public** and will contain digital counter stories by research collaborators who wish to share widely, and briefings of best practices for conducting research with ND community members.



 Create 

 Content

 Blocks

 Files

 Media

☐ Mukurtu Dashboard

 Structure 

 Appearance

 Extend

 Configuration 

 Reports 

 Edit *Neuroqueer Society*

 Shortcuts  Dashboards  Devel

Dashboard

Create Content 

Add Component 

My account

Log out



Communities

Categories

Browse Digital Heritage

Browse

Collections

Diction

[Home](#) >> Neuroqueer Society

You are logged in as the super admin (UID 1), which gives you the ability to take actions that can break the site and corrupt your data. Consider logging into a different account.

Neuroqueer Society

View

Edit

Create Protocol

Manage

Revisions

Devel

A place to share our stories and provide input on respectful research practices for research with neurodivergent community members.

Community role

You are a Community Manager.

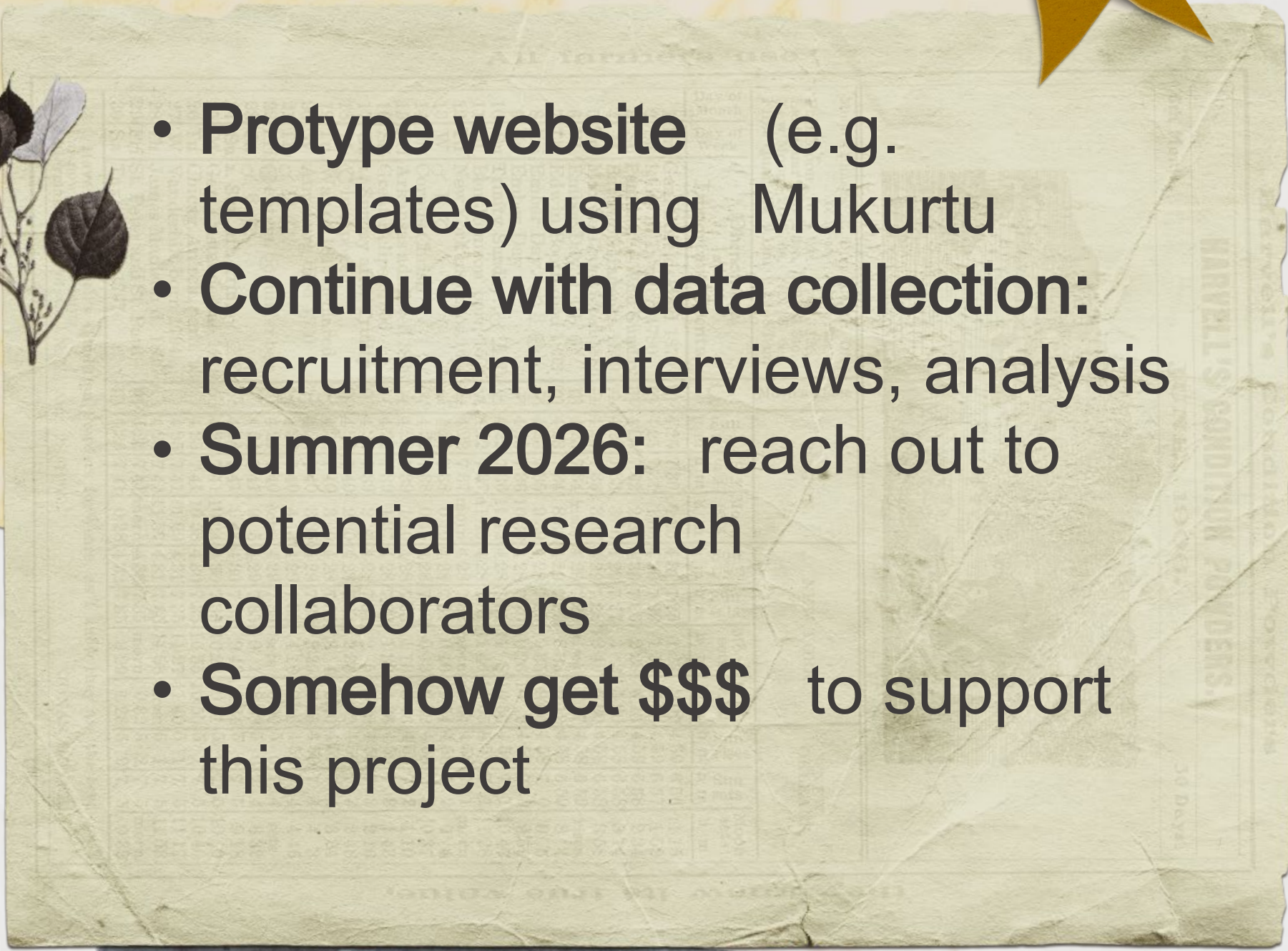
PROGRESS & CHALLENGES

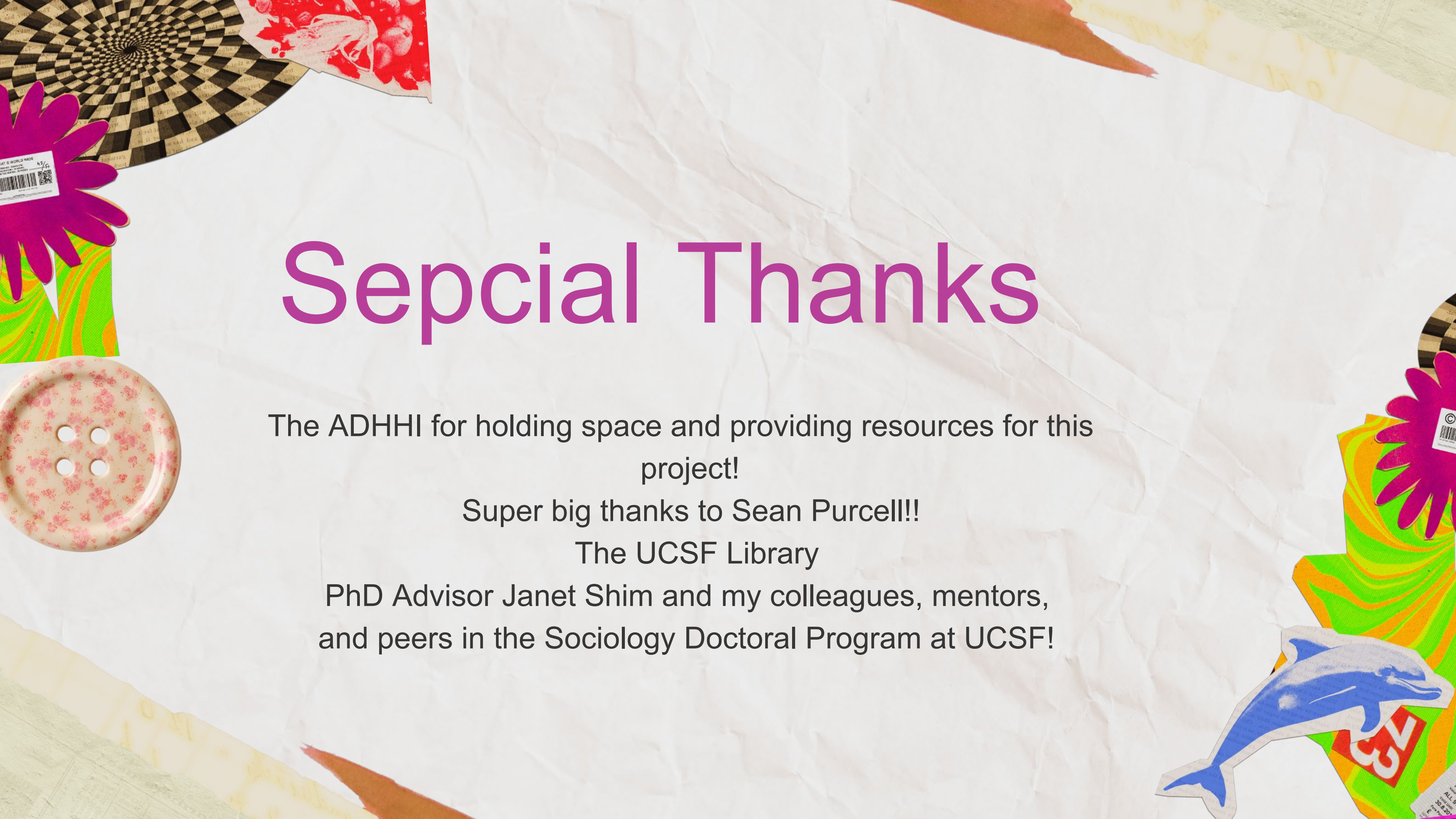


- **Participant recruitment:** 3 interviews;
~ 20+ screening survey responses
 - *Plenty of interest in participation!*
 - *Organizations willing to circulate recruitment material (e.g. ASAN)*
- **We got Mukurtu running** (!!!)
- **Financial Challenges:** No funding
- **Skill Barriers:** Learning how to get Mukurtu running (!!!)



**FUTURE
STEPS**

- 
- **Prototype website** (e.g. templates) using Mukurtu
 - **Continue with data collection:** recruitment, interviews, analysis
 - **Summer 2026:** reach out to potential research collaborators
 - **Somehow get \$\$\$** to support this project



Sepecial Thanks

The ADHHI for holding space and providing resources for this project!

Super big thanks to Sean Purcell!!

The UCSF Library

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and peers in the Sociology Doctoral Program at UCSF!

Thank You

For Your Attention



Contact Me!



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