# Designing a Resilience Resource Database with Hopi Behavioral Health Services


Shelby Hagemann
Northern Arizona University
Flagstaff, United States

Ann Collier
University of Colorado Anschutz
Aurora, United States

Laverne Dallas
Hopi Behavioral Health Services
Polacca, AZ, United States

Marissa Adams
Northern Arizona University
Flagstaff, United States

Darold Joseph
Northern Arizona University
Flagstaff, United States

Ashish Amresh
Northern Arizona University
Flagstaff, United States

Morgan Vigil-Hayes
Northern Arizona University
Flagstaff, United States



## ABSTRACT

Despite high incidence of depression, anxiety, and post traumatic stress disorder, stigma and lack of access to culturally responsive behavioral health care resources prevents many Native Americans (NA) from seeking care. However, the rise of culturally-responsive in-person and digital behavioral health resources for NA communities provides new opportunities to address these longstanding health equity issues. The major challenge is helping people in NA communities find these meaningful resources and helping anchor institutions understand how resources are being sought and utilized to support more responsive internal programming. In this context, we have partnered with Hopi Behavioral Health Services (HBHS) to design the Resilience Resource Database to digitally disseminate mental and behavioral health resources. This paper presents initial findings that have resulted from the initial stage of an iterative participatory design process with HBHS.



## CCS CONCEPTS

• **Human-Centered Computing → User-Centered Design; Participatory Design**.

## KEYWORDS

behavioral health, Native American, rural computing

**ACM Reference Format:**
Shelby Hagemann, Ann Collier, Laverne Dallas, Marissa Adams, Darold Joseph, Ashish Amresh, and Morgan Vigil-Hayes. 2024. Designing a Resilience Resource Database with Hopi Behavioral Health Services. In *Designing Interactive Systems Conference (DIS Companion '24), July 01–05, 2024, IT University of Copenhagen, Denmark*. ACM, New York, NY, USA, 4 pages. https://doi.org/10.1145/3656156.3663736





*DIS Companion '24, July 01–05, 2024, IT University of Copenhagen, Denmark*



ACM ISBN 979-8-4007-0632-5/24/07
https://doi.org/10.1145/3656156.3663736


## 1 INTRODUCTION

Despite the fact that Native American[1] children and adolescents experience the highest rates of lifetime major depressive episodes and highest self-reported depression rates among all ethnic/racial groups in the United States, there is a dearth of culturally-responsive mental health care options for Native American communities [7]. The reasons for these disparities are multifactorial, and involve rurality, constrained political and economic power of tribes, and the ongoing contentious and oppressive relationship between the US government and Indigenous people living in the United States [4, 6].

In this broader context, Hopi Behavioral Health Services (HBHS) is an organization within the Hopi Tribe that provides behavioral health support and aid to the Hopi community. The Hopi Tribe is a sovereign Indigenous nation based in rural northeastern Arizona, with a population of 9,268 people living across three mesas over 1.5 million acres. As part of an ongoing partnership between our research team and HBHS, we held a series of meetings with their staff members to understand how technology could work with the Hopi community to promote a "smart and connected" community that centered the needs of Hopi youth. During these meetings, several staff members expressed that their services could be more effective for Hopi youth if they were able to reach them digitally. However, they noted that finding Hopi or Native American-specific resources for behavioral healthcare through a common search engine, such as Google, is immensely difficult, as the search results are often over-saturated with non-specific resources, which often come from a white or Western perspective. Moreover, they noted that a more centralized information system that would allow them to automatically collect data about community mental health needs could help make Hopi community programming more responsive to Hopi people.

In partnership with HBHS and in response to these visioning meetings, we are co-designing a Resilience Resource Database (RRDB) for the Hopi community. In this paper we describe our initial prototype and process of collecting feedback from HBHS staff through a focus group. Specifically, we identify that one of the most important needs of HBHS is accommodating people seeking

[1]While many academic and government resources use the term "American Indian/Alaska Native", the preferred term by Indigenous people in our region is "Native American."

out resources for their loved ones, who we refer to in this paper as information mediators. Additionally, we found that we must implement more features within the RRDB to center its functionalities around the presence of grief and ensure that it is usable for people with limitted internet connectivity.

## 2 RELATED WORK

Hopi people practice resilience against the impacts of colonization through cultural traditions and knowledge. Indeed, as part of our collaborative effort with HBHS, we seek to center these strengths in the design of the RRDB by digitally increasing the legibility of resources that reflect Hopi values. Digital artifacts within the technology and design process spaces have historically been developed from Western, educated, industrialized, rich, democratic (WEIRD) perspectives [5]. Consequently, Indigenous communities are underrepresented in the design of digital artifacts. As described by To et al., Indigenous representation in digital artifacts is often limited to deficit and damage-centered research[5], further limiting their representation.

The ways in which Indigenous communities are represented in digital artifact design is flawed. To et al. examine a sense of "othering" that BIPOC communities, such as Hopi, often face, which requires that they recenter their experiences around WEIRD perspectives. These authors emphasize the importance of using these technologies in building up BIPOC communities, exemplifying their values and beliefs in ways that promote cultural revitalization. Finding a balance between promoting cultural beliefs and values and maintaining these components as tertiary aspects of the software, to avoid trivializing the community is crucial[5].

Many Indigenous communities are reluctant to participate in the design of these artifacts, also contributing to this lack of representation. To quote Linda Tuhiwai Smith, "'research' is probably one of the dirtiest words in the Indigenous world's vocabulary"[6]. There is a global history of colonizers and oppressors using unethical research practices with Indigenous people, with results being more extractive than collaborative[6]. This has led to concerns among Indigenous communities regarding the sharing of cultural knowledge [1]. Additionally, Indigenous communities, such as Hopi, often experience an intergenerational form of complex trauma, which results from longstanding histories of oppression. This form of trauma, sometimes referred to as "historical trauma" impacts not only the direct recipients of oppression and abuse, but those close to them as well [4].

## 3 METHODOLOGIES

### 3.1 Pre-Design

In 2021, our research team met with Hopi community members as part of a participatory action research project for addressing mental health concerns surrounding Hopi youth. Addressing some of the challenges associated with mental health in collaboration with HBHS program managers, counselors, school counselors, parents, and grandparents, we identified an emergent theme: a need for new ways to disseminate mental health resources while keeping track of which resources Hopi community members were looking for in a way that was sensitive to their small community. During this time, mental and behavioral health resources were shared in the community through through a paper flyer, which contained addresses and phone numbers for various programs and hotlines. However, with more youth and their parents turning to the Internet to seek out resources, HBHS wanted to *"meet people where they are at"* (P1) by converting this paper flyer into a digital format.

We used this meeting as an initial assessment of needs and potential for what a *resilience resource database* for the Hopi community would entail. We identified several important requirements that stakeholders agreed on: people looking for resources should maintain (and feel secure about) their anonymity to avoid stigmas surrounding mental health; resources should be vetted for cultural appropriateness, with those being particularly culturally-responsive or grounded being highlighted; resources should be vetted for providing evidence-based support; HBHS should be able to access aggregate search queries to understand patterns in the types of resources the community was searching for and which types of resources they were most likely to "click on" to access. Additionally, we also knew from our conversations and partnership with Hopi that Internet connectivity was a logistical factor that individuals negotiated with to determine when or where they were able to do certain tasks. Thus, we also added the requirement that resources needed to indicate the type of connectivity required for access.

### 3.2 First Prototype

The RRDB was programmed through Flutter and Dart, utilizing Google Firebase for the backend. We designed the database to operate for two groups of people–general users and administrators. General users are anyone searching through the database for resources and can share resource information via text or email. Administrators are HBHS staff, who submit new resources into the database and verify the cultural appropriateness, evidence-based correctness, and connectivity requirements for newly submitted resources. To remove bias from the resource verification process, administrators can only approve or deny resources submitted by other administrators.

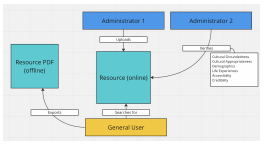


**Figure 1: Entity Relationship Diagram for the RRDB**

### 3.3 Focus Group

In August 2023 we demonstrated the prototype at a HBHS staff meeting and collected feedback on it. This meeting took place in one of the tribal community centers in Second Mesa, which requires people using it to bring their own audio/video infrastructure. Using our own projector screen, a laptop, and a mini projector, we demonstrated accessing the database through the web. This focus group lasted one hour and consisted of 15 consented participants total, 4 of whom were male and 11 of whom were female. Each participant was a member of HBHS staff with experience working with Hopi youth and families, as well as creating, facilitating, and distributing resources for mental healthcare and resilience. Indeed, most staff

members are also members of the Hopi community. Prior to holding the focus group, we populated the database with a variety of resources, many of which are already offered through HBHS. We introduced our software to the participants, explaining it's purpose and key functionalities.

After displaying the basic functionalities of the RRDB, participants had a general idea for it's workflows and functionalities and were given a link to the live version of the platform so they could use it on their own devices. Most participants accessed the database on smartphones, however some accessed it on laptops. We asked them to search for resources within the database and vocalize concerns or issues as they arose. After each participant used the prototype, we began a formal group debriefing session.

### 3.4 Data Analysis

We followed the process of grounded theory analysis[2], asking participants questions to generate new feedback and ideas for the RRDB's design. The first author went through the focus group transcript and organized individual quotes by theme. The second author then examined the transcript and her field notes and identified additional themes. Together during a single coding session, the first and second authors generated a set of six axial themes and twenty total open codes related to additional design needs identified by the focus group. These axial themes included: Focusing on specific resource areas; Expanding types of resources offered; Designing for confidentiality; Designing for accessibility and sensitivity; Display of resource information; and Collecting community information.

## 4 FINDINGS

### 4.1 Accessibility

We discussed ways in which the web platform could be made more accessible and beneficial to a wider audience. Several HBHS staff members noted during our discussion that many of their clients experience difficulty reading and *"prefer to have somebody read their patient documents to them"* (P1). HBHS already has several practices in place for addressing this issue that we can implement into the RRDB. For example, all written materials are written at a fifth grade reading level, to remain inclusive both to younger audiences and those with difficulty reading.

### 4.2 Omnipresent Grief

One theme that was frequent within our discussion with HBHS staff was grief. Several staff members expressed the importance of understanding and meeting the needs of their community, especially after a tragic event has taken place. HBHS staff must be able to view analytical data on what members of their community are searching for and what resources they are actively engaging with surrounding specific dates (primarily dates following a death in the community). For HBHS, it would be important to see *"if there was a suicide or another tragic event that happened, we'd like to know what the community is [doing], are they utilizing the database"* (P4). In addition to monitoring the frequency of the RRDB's use, several HBHS staff members expressed interest in viewing demographic information on people searching for resources, assuming confidentiality could be maintained. One participant explained the importance of *"being able to look at for an age category if a lot of them are looking for ways to cope with something or ways to abstain from something"* (P4), as it would give HBHS guidance in planning future events or resources for their community.

### 4.3 Supporting Information Mediators

A large part of the RRDB's usage will likely be from information mediators. These people often reach out to HBHS to find resources for others. For this reason, we must not only take into consideration for future development the aid receivers, but the information mediators as well. This demand for support for information mediators was shown through the types of resources that staff members wanted to be show on the database. For example, parents often contact HBHS for help for or relating to their children, which was explained by one participant who wanted to see *"a system set up for parents looking for resources, like words of affirmation, 'what should I do as a parent?'"* (P4).

Some staff members expressed concerns regarding digital literacy among different age demographics, with one participant explaining that parents, grandparents, or elders may have difficulty searching for resources online, stating *"it would be helpful if it was easy to access because I don't know how many parents can search through it online"* (P2). One of the inspirations for creating the RRDB came from HBHS staff members wanting to meet the needs and interests of youth in their community, who use the internet more frequently than older generations. However, this tool needs to be accessible and useful to all generations and members of their community, regardless of their experience using the internet, especially considering that many people, such as elders or parents, may use it for finding resources for their loved ones.

### 4.4 Closing the Loop

Usage data from the RRDB would aid HBHS staff in identifying needs within their community as they emerge from different community events and seasons. Participants offered a variety of suggestions for what could support this goal. For example, HBHS staff must understand how often a given resource is "clicked on" by users and *"which resource is being contacted the most"* (P8). Additionally, understanding how often different search filters are used is important. For instance, HBHS staff would want to know if there was an uptick in people looking for resources dealing with grief or depression. Moreover, staff must know know *"how [users] are finding the site"* (P4). HBHS should know which websites and QR codes linking to the RRDB are being leveraged to support this.

HBHS staff emphasized the importance of knowing whether a user was on or off the Hopi reservation when they were seeking resources, with the goal being to help inform partners inside and outside the Hopi community to better serve emergent needs of Hopi people. Ultimately, this information could be used in developing a formal or informal service referral network in the future. Addressing the omnipresent challenge of grief coping, staff members also suggested that data should be able to be centered around specific dates to reveal communal responses to different events. One participant explained *"if there was a suicide or another tragic event that happened, we'd like to know what the community is [doing], are they utilizing the database"* (P4).

Additionally, HBHS staff members wanted to know how different resources are perceived by members of the Hopi community. Several participants in our focus group suggested obtaining this data through anonymous user-feedback surveys, which could either be randomly offered to users of the RRDB or offered at any time if someone would wish to provide feedback for a specific resource. Users could also be able to rate their opinion of a particular resources. While many agreed that this would be useful, several participants emphasized the importance of stewarding reputation information, focusing on relationality and constructivism, avoiding diminishing the reputation of a given resource. One staff member explained this importance, stating *"It would just be an internal thing, because we don't want to jeopardize anyone's program with somebody's negative feedback"* (P1). Indeed, the feedback could be used to moderate constructive feedback to help improve different programs and services within the community.

# 5 DIRECTIONS FOR FUTURE WORK

## 5.1 Design for Information Mediators

Based on our findings in Section 4.3, we know that we must consider information mediators and their needs during further development. For example, the RRDB can be designed such that users can easily share materials with others either through text, email, or exporting resource information as PDFs for printing. To ensure that the RRDB is accessible and useful for information mediators and resource recipients alike, we must take varying digital literacies into consideration in further development. The RRDB must be designed such that it can be comfortably and effectively used by all age demographics among the Hopi Tribe that have access to the internet. Each generation within the Hopi community will have different levels of technological awareness. This issue can be addressed by restructuring future co-design sessions so that participants represent a broader variety of ages, offering a wider range of perspectives. Additionally, this issue could be addressed with help from an AI chat-bot. Existing research exhibits that chat-bots show potential in alleviating stress and bridging gaps among varying digital literacies [3], which could be vastly useful for the RRDB's users.

## 5.2 Designing the Dashboard to Close the Loop

As discussed in Section 4, HBHS staff members expressed that it was important for them to be more concretely aware of grief in the community. The analytical data displayed through the dashboard must be designed such that it signifies the presence of community-wide, complex grief on Hopi in a way that is useful to HBHS. This data could be collected in a number of ways, such as using users IP addresses to determine whether or not they are on Hopi and which Mesa they are located on. The RRDB could also randomly ask users to complete an optional demographics survey, in which they would be ask demographic questions and whether they are searching for themselves or someone else. When collecting this analytical data, however, it is crucial to maintain anonymity for users, as HBHS staff expressed that a lack of privacy may deter people from using the RRDB. The dashboard can also provide a space for feedback for partners both inside and outside of the Hopi community. Several HBHS staff members expressed an interest in being able to provide discrete, anonymous feedback to services to help them improve in quality. HBHS staff could view this feedback and then determine whether or not they would like to disclose the statements with their partners.

# REFERENCES


[1] Miranda Belarde-Lewis. 2011. Sharing the private in public: indigenous cultural property and online media. In *Proceedings of the 2011 IConference* (Seattle, Washington, USA) *(iConference '11)*. Association for Computing Machinery, New York, NY, USA, 16–24. https://doi.org/10.1145/1940761.1940764

[2] Barney Glaser and Anselm Strauss. 1999. *Discovery of Grounded Theory: Strategies for Qualitative Research.* Taylor and Francis Group, Milton Park, Oxfordshire, United Kingdom.

[3] Othelia Eun-Kyoung Lee and Do-Hong Kim. 2019. Bridging the Digital Divide for Older Adults via Intergenerational Mentor-Up. *Research on Social Work Practice* 29, 7 (2019), 786–795. https://doi.org/10.1177/1049731518810798

[4] Linda O'Neil, Tina Fraser, Andrew Kitchenham, and Verna McDonald. 2016. Hidden Burdens: a Review of Intergenerational, Historical, and Complex Trauma, Implications for Indigenous Families. *Journal of Childhood Adolescent Trauma* (2016), 173–186. https://doi.org/10.1007/s40653-016-0117-9

[5] Alexandra To, Angela D. R. Smith, Dilruba Showkat, Adinawa Adjagbodjou, and Christina Harrington. 2023. Flourishing in the Everyday: Moving Beyond Damage-Centered Design in HCI for BIPOC Communities. In *Proceedings of the 2023 ACM Designing Interactive Systems Conference* (Pittsburgh, PA, USA) *(DIS '23)*. Association for Computing Machinery, New York, NY, USA, 917–933. https://doi.org/10.1145/3563657.3596057

[6] Linda Tuhiwai Smith. 2012. *Decolonizing Methodologies: Research and Indigenous People (Second Edition).* Zed Books, London, United Kingdom.

[7] Mira Zein and Mary Rossel. 2017. Mental Health Disparities: American Indians and Alaska Natives. *American Psychiatric Association* (2017). https://www.psychiatry.org/File%20Library/Psychiatrists/Cultural-Competency/Mental-Health-Disparities/Mental-Health-Facts-for-American-Indian-Alaska-Natives.pdf