Participatory visual methods for American Indian communities and mental health conversations

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Abstract:

Visual methods serve a unique purpose in that they help generate data that uncover experiences, knowledge, and contextual factors that lead to a greater shared understanding about a topic. We describe the process and results of one American Indian community-based organization's success using visual methods to prompt community conversations about mental health and substance abuse. We uncovered community members' mental health perspectives and experiences through visual vignettes. Our hope is that other communities and funding agencies see the value and promise of visual methods as a valid approach that promotes shared dialogue, decision making, and conversations for future generations.

Keywords: visual methods | mental health | substance abuse | American Indian community

Article:

Background

Participatory research methods engage diverse groups in discussions and collaborations that often result in social change and improved health (Jason et.al, 2004). Visual images (e.g., photographs, drawings, paintings) are tools used in participatory research methods to prompt dialogue between researchers and community members. In American Indian (AI) communities marginalized by colonization and dominant Western research paradigms and worldviews (Kelley et.al, 2013), participatory research methods and visual images are appropriate. Images can help communities think critically about sensitive and highly personal issues like substance abuse or mental health challenges, while creating opportunities for in-depth discussions and exploration in a variety of community settings. In contrast, traditional Western research uses written reports, statistics, and sophisticated language to convey information—such approaches often alienate community members. Funding agencies and federal programs often prefer Western research approaches, yet these approaches may fail to demonstrate cultural sensitivity or in-depth

understanding about the economic, social, cultural, and contextual differences that define communities. This lack of understanding ultimately leads to flawed program approaches promoted by federal agencies and unrealistic expectations for communities and community-based programs (Gone, 2004; Gray, de Boehm, Farnsworth, & Wolf, 2010).

There is a disconnect between funding agencies and communities where Western psychology, ideologies, and epistemologies are often deeply rooted in program approaches and funding streams that do not work for AI communities. The power, control, and economic interests of federal agencies may unknowingly subjugate culturally marginalized groups, like AI communities to harm. Evidence of hegemony can be found in federal funding agency protocols and demands based on Western ideals and infrastructure, including extensive data collection, evaluation, clinical resources, and sophisticated studies that promote Western definitions and concepts of mental health systems and needs.

There are fundamental differences in how some AI communities view mental health systems and needs compared to federal agency definitions. For example, funding agencies like the Substance Abuse and Mental Health Services Administration (SAMHSA) often define a mental health system of care as:

A spectrum of effective, community-based services and supports for children and youth with or at risk for mental health or other challenges and their families, that is organized into a coordinated network, builds meaningful partnerships with families and youth, and addresses their cultural and linguistic needs, in order to help them to function better at home, in school, in the community and throughout life. (Stroul, Blau, & Friedman, 2010, p. 1)

It could be argued that this federal agency definition tries to be broad-based, inclusive, and respectful of cultural differences. However, many AI communities are disaffected by the terms *mental health* and *system of care* because of (1) the oppression and colonization they have experienced, and (2) the fact that these concepts are foreign to many communities. AI communities may view mental health systems and needs as one part of the broader social, cultural, and spiritual context. In fact, some AI communities historically did not have a word for "mental health needs," and, according to a tribal elder (tribal elder/advisor, personal communication, March 15, 2013), the closest term for mental health needs in one Native language would translate to "those who could not listen." Prevention efforts in reservation communities may be complicated by the fact that, under the federal agency definition of mental health, individuals are assigned labels or diagnoses that historically had no meaning or relevance, and therefore do not exist based on AI community standards and worldviews.

New Methods for Prompting Mental Health Conversations

New methods that give voice to historically marginalized populations through a common language and shared dialogue are needed to promote a shared understanding of mental health systems and needs as well as solutions in AI community settings. This paper describes the use of visual methods (vignettes) to engage AI community members in conversations about mental health systems and needs for families and youth.

Visual Methods and Indigenous Inquiry

Arts, imagery, crafts, oral traditions (e.g., storytelling), and painting are part of the unique history of all cultural and ethnic groups (Gray et. al, 2010). For early AIs, drawings served as

visual depictions (stories) of events that happened in their lives, including battles, ceremonies, and everyday living. Among Indigenous groups, '…story and knowing cannot be traced back to any specific starting time within tribal societies, for they have been tightly bound since time immemorial as a legitimate form of understanding'(Kovach, 2010, p. 95). Visualization and imagery remain an important part of AI cultures and knowledge transmission in the present day. Visual methods serve a unique purpose in that they help generate data that uncover experiences, knowledge, and contextual factors that lead to a greater shared understanding about a topic (Baker & Wang, 2006). They are used most appropriately to 1) convey information about a given community's strengths and challenges; 2) prompt sharing of information that often is sensitive in nature; and 3) elicit responses, experiences, and perceptions about sensitive topics that are not conveyed through more traditional means. Visual methods also allow for artistic expression that is universal and does not depend on language or education level. In addition, these methods are appropriate for cultivating relationships among community-based program personnel and their fellow community members, consultants, and federal program officers (Gray et.al, 2010). Visual methods are an effective way to reach youth, young adults, and individuals with lower literacy levels or those who would not be reached through traditional data collection efforts (e.g., surveys, key informant interviews, focus groups), and to encourage community participation, dialogue, and engagement (Freire, 1970; Wallerstein & Bernstein, 1988). Such methods can be used to confirm or validate the experiences and needs of community members without making people feel defensive, which is critical when topics like mental health systems and needs are discussed.

Indeed, the use of visual methods can prompt social action by helping community members prioritize concerns, build on strengths of culture, and advocate for improvements (Gray et.al, 2010). In research, visual methods are particularly useful when community-based programs already have a general idea about the needs, experiences, and beliefs of individuals based on formative data like that gained from focus groups, surveys, community reports, and presentations.

Theory

The theoretical underpinnings of visual methods come from the work of Paulo Freire (1970), a Brazilian educator who conceived much of what is written about empowerment education theory and critical consciousness. Building on Frantz Fannon's (1965) psychiatric and psychologic analysis of the dehumanizing effects of colonization, Freire's work sought decolonization of all people, including Indigenous populations throughout the world. Critical consciousness is based on achieving an in-depth understanding of the world while taking action against oppression that comes from a lack of understanding (Wallerstein & Bernstein, 1988). Although critical consciousness first started in education, much of Freire's work extended into health education, research, and policy and program implementation in community-based settings (Bernstein et al., 1994; Wiggins, 2012). Visual methods are theoretically driven and are based on empowerment and social action processes that call for community participation, identifying a problem, solving a problem, and giving voice to people and experiences that often are ignored or not reached through traditional research or data collection methods (Davis & Harrison, 2013). In light of this illuminating power, authors and communities have built on Freire's work and described their successes with visual methods in communities where populations have a distrust

of Western research approaches and dominant worldviews (Banks, 2001; Bernstein et al., 1994; Thomson, 2009).

Objectives

This case study describes how one AI community-based organization (CBO) developed a culturally relevant visual methods data collection strategy to document and confirm mental health systems and needs, resources, and perceptions of community members. The overall purpose of the 3-year project, funded by SAMHSA, was to plan and develop a system of care on the reservation for children and families with serious mental health needs. In the first 2 years of the project, the project team used traditional methods like surveys, focus groups, and community gatherings to collect information from the community on mental health systems and needs and substance abuse; however, this case study describes how visual methods were used later to uncover the contextual, cultural, and community factors related to mental health systems and needs on the reservation. This approach was more culturally relevant and sensitive to the experiences of community members.

Methods

The project team, which consists of the CBO's chief professional officer, the grant project director, a data coordinator, four program partners, two cultural consultants, and an evaluation scientist, followed a three-step process based on the early work and recommendations of Freire (1970). First, they listened to understand the mental health concerns and issues of youth and families. Second, the team created what Freire called "codes" (here called visual vignettes) that illustrated community-identified issues. Last, the team recorded and shared information from community members about what they wanted to see change in the community that would help improve mental health systems and access to resources.

The team submitted the protocol for this study to the executive board of the CBO, which gave the team final approval. The team followed the local tribal protocol; because tribal protocols vary, teams in other communities may need to submit visual data collection methods to an IRB of record prior to collecting information.

Community Context and Setting

The AI community is located in Montana and is home to one federally recognized tribe. The location is rural and designated as a medically underserved area. Mental health services are offered through the tribe, and limited substance abuse treatment options are available.

The Project Team's Partnership

The partnership started in 2010 when members of the CBO attended a workshop taught by the evaluation scientist to learn more about resource coordination and support for tribal mental health programs. Together, the team developed a plan to address unmet mental health needs for children and youth in the community; one goal was to secure funding to support planning for a mental health system of care. The evaluation scientist was not affiliated with an academic institution, allowing for more flexibility and trust building in the partnership process.

Program

The team received funding from SAMHSA in 2011 and worked closely with other tribal health programs, including behavioral health, recovery, Bureau of Indian Affairs, social services, and schools. Cultural leaders, elders, and natural helpers also supported the program as advisors and cultural resources. (Natural helpers are individuals from the community with traditional and spiritual gifts who do not fill traditional 'helping' roles or professions as defined by Western standards, but nonetheless provide essential advice and assistance.) A community advisory board provided oversight and included representatives from youth- and family-supporting organizations, cultural programs, public and tribal schools, social service organizations, law enforcement, juvenile justice, and CBOs, as well as traditional knowledge keepers and elders.

In the first 2 years of the project, the team tried traditional data collection methods to gather information about mental health systems and needs, including a 19-question paper-and-pen survey sent to providers that asked questions about the kinds of mental health resources available, client demographics, and provider demographics. This needs assessment was the first step in the 3-year planning process of documenting the existing mental health services that would later be used to create a system of care on the reservation. After the needs assessment, the team conducted focus groups with community members to document their perspectives about gaps in existing mental health services. The team also tried to gather information via surveys, interviews, community gatherings, and secondary data analysis. However, many community members were reluctant to talk about mental health, and these traditional data collection methods resulted in data that were difficult to link with mental health systems and needs. For example, widespread poverty and a lack of community activities were common responses to mental health-related questions. In the 3rd year of the grant, the team decided to try a different approach and developed a data collection strategy that was relational and intuitive. Ultimately, the team wanted to explore and confirm the issues, barriers, and resources on the reservation. Over several months, the team developed visual vignettes of different scenarios people may experience as they navigate the mental health system on the reservation (e.g., cutting behavior, prescription drug and alcohol abuse, mother addicted to drugs wanting to get her kids back). These were vetted by the team and various stakeholders using the following process: The evaluation scientist sent electronic copies of the vignettes to the data coordinator, project director, and CBO for review and comment. After the evaluation scientist incorporated their comments, the data coordinator and project director asked several community advisory board members to review the revised vignettes which served as a pilot process. This process resulted in two additional visual vignettes: a veteran and a transgendered youth. A total of six vignettes were used in the participatory data collection process.

It is important to note that, within this method, story and drawings make more sense to those who have experienced or seen the events occur in their community—these vignettes are very specific to what happens in this reservation community. Someone without knowledge of the context, history, location, and norms may not understand or benefit as much from this method. However, the scenarios created by the team may help those without knowledge to gain understanding about the unique community context. For example, professionals working with Native veterans returning to their reservation may not be aware of how veterans access resources in their communities, or of the strong kinship systems and family support that help veterans when they return home. Some professionals may not understand, for example, the distrust of

Western behavioral health providers, the use of pills to treat anxiety, or the limited employment opportunities on reservations. The veteran vignette outlines this process and lists other resources that are available on the reservation, many of which are available in other reservation communities as well. See Appendix A for all vignettes.

Participatory Visual Data Collection

Informants were identified using a convenience sampling method, where the data coordinator, trained by the evaluation scientist, approached people in a variety of community settings and asked them to look at 8.5" x 11" color printouts of the visual vignettes and answer questions about them. (Note: The vignettes were referred to as *diagrams* during these interviews because *visual vignette* is not a commonly used term on the reservation.) The data coordinator also went to all five districts on the reservation and approached people outside community locations (e.g., post office, community meeting hall). The data coordinator gained verbal informed consent for all participants interviewed, and the team followed local protocols for data collection, analysis, dissemination, and reporting, as well as ethical standards of research for the community. Participants did not receive compensation. No participants mentioned privacy concerns, although it is possible that some individuals approached were not comfortable talking about mental health on the reservation and therefore declined to participate. The majority of people asked by the data coordinator agreed to participate in the interviews; however, the team did not record the number of people asked and the number of people who refused.

Participants

Interviews were conducted in March and April 2014 with community members over 18 years of age ($N = 25$) who represented various perspectives, ages, and genders, as well as all districts in the community. The team decided that 25 responses were sufficient based on the resources and time available, and on similarities in experiences shared by community members.

Questions

Community members were asked a series of open-ended questions, including:

1. What do you think about these stories/experiences illustrated in the diagrams?
2. Are these situations similar to what people on the reservation experience?
3. What other mental health resources are available in the community?

In some cases, community members looked at the diagrams and wrote directly on them; sometimes they used lines to show how they felt the experiences did not reflect what actually happens in the community, and they redirected the arrows and order of events (see Figure 1). With other informants, the data coordinator wrote down information using a paper and pen. All paper documents were converted to electronic format either by scanning or by typing responses into Microsoft Word; the electronic versions then were sent to the evaluation scientist for analysis.

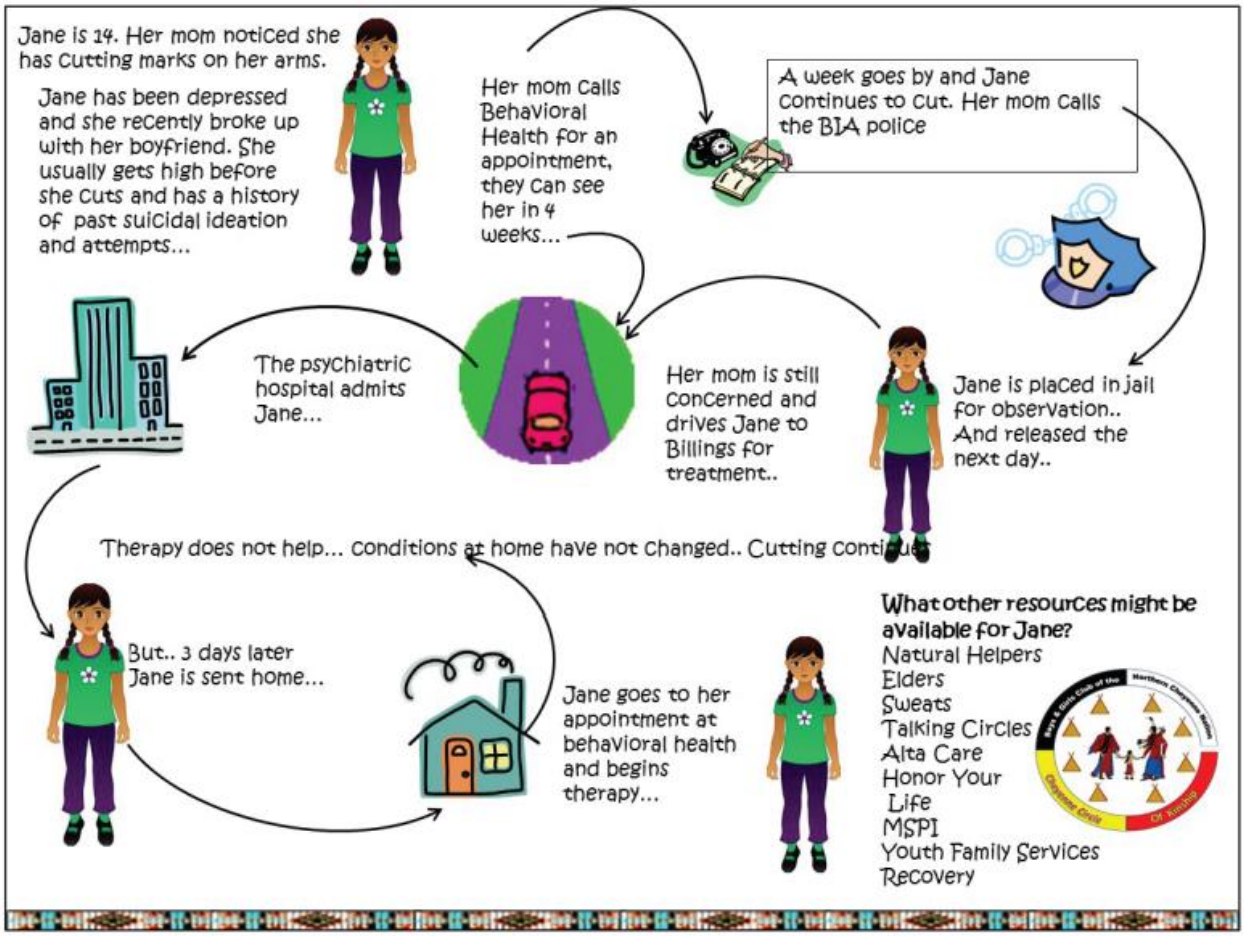
Analysis

The team was most interested in a visual representation of themes and the relationships between them; therefore, they selected a thematic network analysis approach (Attride-Stirling, 2001). All data were uploaded into ATLAS.ti by the evaluation scientist (Muhr & Friese, 2004) to ensure the themes illustrated were supported by the responses and to see how they were related. Themes then were reviewed by the team, community members, and program personnel to ensure they represented the actual experiences and perceptions of people in the community. The team followed an Indigenous research approach that allowed for inquiry and exploration of the dominant and traditional research paradigm of mental health systems and needs on the reservation. This approach was most appropriate for the community and included a participatory decolonizing framework designed to promote self-determination and cultural autonomy with the goal of justice and equity (Denzin, Lincoln, & Smith, 2008).

The analysis process required several steps. The first step was to devise a coding framework and then to open code text. Next, themes were abstracted from coded text segments and refined. Thematic networks were created by arranging basic and organizing themes and extrapolating global themes. These networks then were illustrated and refined based on the project team's review and consensus. Networks then were examined to find meaning between themes and patterns that emerged from the process.

In the last step of the analytic process, the team organized the themes based on the following categories: strengths, challenges, recommendations, culture and spirituality, access and quality, and general statements. Data generated from visual methods then were used to refine diagrams describing the mental health systems and needs on the reservation.

Figure 1
Examples of Visual Vignette Presented to community member to Prompt Dialogue



Results

Visual methods helped the team elucidate concepts, stories, and experiences related to the mental health systems and needs on the reservation.

The global theme that emerged was expanding the use of culture and existing cultural resources for youth and families with various unmet mental health needs. This theme was linked with other organizing themes, including the community history and context, where strengths and challenges were described by community members. Another organizing theme was recommendations about how to improve mental health and substance abuse resources with regard to access and quality (see Figure 2). (Most participants did not distinguish substance abuse from mental health needs. For example, some people talked about wanting to get help for their family members who struggle with substance abuse and depression.)

Many community members talked about the use of spiritual leaders, the connection to cultural resources, and the use of elders to teach and reinforce culture. This finding was documented by the team early on, but not in the context of specific mental health needs. Community members voiced specific recommendations based on the circumstances outlined in the visual vignettes. Several conversations related to the need for improved law enforcement response to mental health crisis situations, improved clinical care, and challenges within the family environment where drinking and drugs are present. Also, many community members talked about the need for better access to and quality of mental health services (e.g., lack of culturally competent

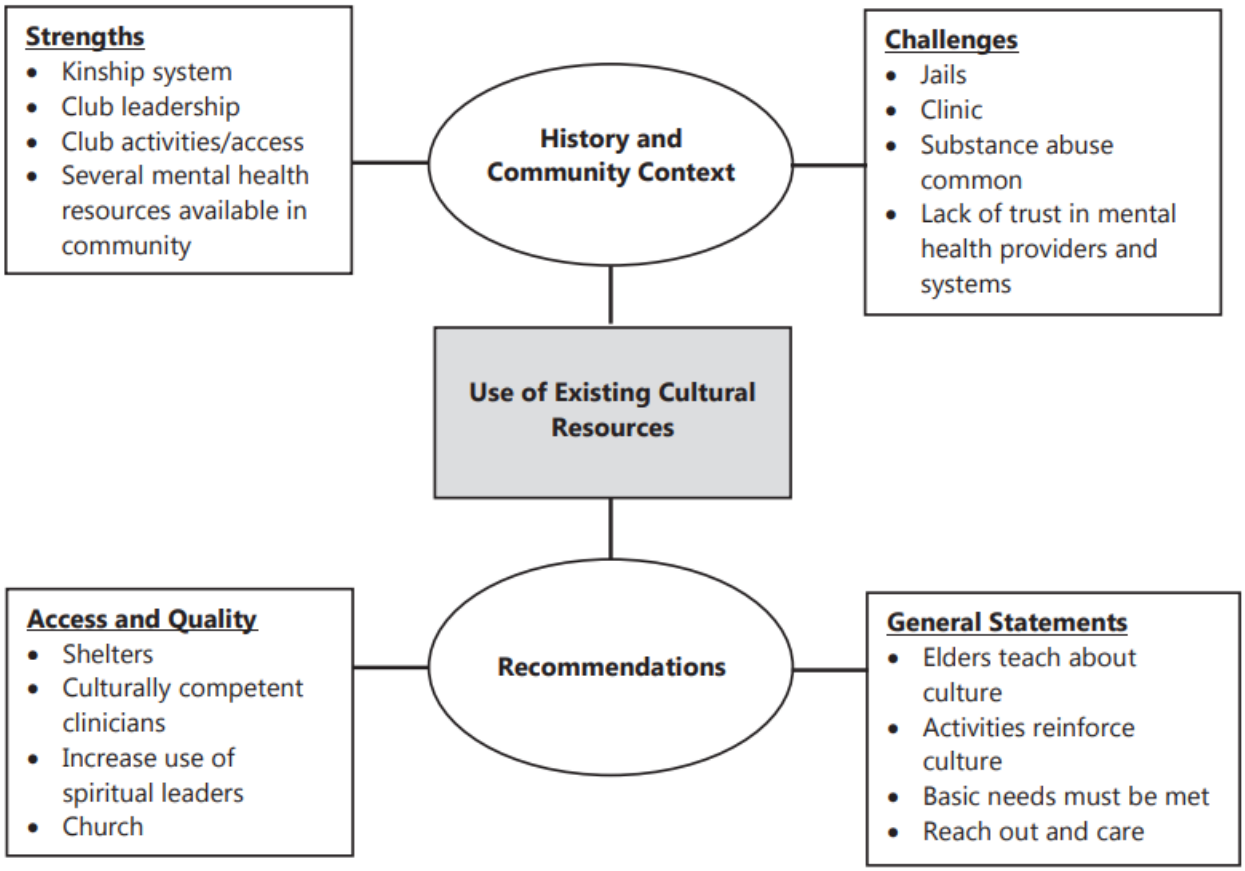
providers). Community assets and strengths were echoed in many conversations, where the Boys and Girls Club was mentioned as a positive place for community activities and leadership building in youth. Other conversations related to using existing mental health resources in the community, and many recommended efforts to increase community awareness about mental health resources on the reservation. Due to the sensitive nature of mental health conversations in the community, specific statements are not included in this paper.

In summary, this process uncovered both strengths and challenges related to the current mental health system of care on the reservation. The team hopes to focus on the challenges uncovered through this process to improve conditions and access. For example, to address the lack of culturally competent mental health providers and the differing views about the definition of mental health needs, the CBO plans to promote mental health awareness through CBO staff trainings, professional development opportunities, partnerships with behavioral health programs, and continuing mental health conversations in the community.

Limitations

Visual methods in research present limitations, mainly because the process is subjective and there are limits to what one can observe in a drawing. Words were used in the visual vignettes to tell stories about how individuals accessed different mental health systems on the reservation. Not all stories were captured through this time-intensive process; therefore, the results and feedback provided by participants may not represent the entire community or the experiences of all community members. The results of this effort are not generalizable to other tribes or communities; however, the team feels the approach is transferable to other communities. To this end, the team created a blank visual vignette that could be used by other tribes; it includes areas for need, context, resources, and discussions. However, the use of visual methods requires an initial understanding about context and needs—if communities do not have preliminary data or information, visual methods may not be appropriate. Also, the participants' responses and openness rely heavily on the individual leading the discussion. The data coordinator in this study was comfortable with these conversations and was well respected in the community, so trust was already established and the information shared was honest and open.

Figure 2
Thematic Analysis: History, Cultural Resources, and Recommendations



For nearly 3 years, the team, advisory board members, and grant project officers used a variety of words to define mental health system and needs. These words meant different things to different people, which created confusion and feelings of inadequacy among team members. The team learned two lessons from this experience. First, it's important to think creatively when traditional research approaches fail to deliver needed information. Second, dialogue about mental health systems and needs must begin with the people. Visual methods served as the most effective approach to these conversations.

Next steps

In the future, communities and funding agencies must consider the reasons information is requested by funding agencies and generated in communities. The project team learned early in the 3-year process that the generation of information without a clear purpose is not always valuable to community members and rarely improves the conditions for which the information is requested. In the first 2 years of the project, the team tried traditional data collection methods and found that community members were reluctant to talk about mental health; yet, in the 3rd year of the project, when the team started using visual methods—people started to talk, and the team listened.

Several lasting effects came from the insights gained through the team's use of participatory visual research methods. First, the team developed a deeper understanding of how the community views and experiences the mental health system of care on the reservation. This understanding pointed to the unique strengths and challenges in the community. The CBO plans to build future programs and services using the strengths identified through this process,

including community awareness and resources such as strong kinship systems, existing mental health providers, spiritual leaders, and elders. Second, a drug task force coalition was revitalized in the community, supported by the stories and experiences shared by community members through visual vignettes. Third, leadership in the community for mental health-related training and capacity increased. Both a community and a youth advisory board met every month to discuss the mental health needs of youth and families on the reservation. In sum, this process increased mental health awareness in the community and translates to improved screening, identification, and referral for individuals in need.

In closing, visual data collection methods as a research strategy worked to instill trust between the community and the research team. Visual vignettes were more effective in reaching community members than were traditional approaches, and served as a common ground that uncovered community members' perspectives about and experiences with mental health systems and needs, as well as substance abuse. The relationships developed through this process helped community members share their experiences and knowledge in a manner that was safe and relevant to the community. This knowledge, in turn, helped the team understand and document community voices regarding mental health systems and needs on the reservation, and to integrate findings from across demographics, reservation districts, genders, and age groups. Ultimately, the visual data collection process was effective and promoted community ownership, engagement, and feedback.

In the future, the team plans to continue using visual methods for information and data gathering—especially when sensitive and highly personal topics are discussed. In doing so, the team hopes to empower community members as advocates of social change while promoting the rich history, language, values, arts, and aspirations of community members for healthy future generations.

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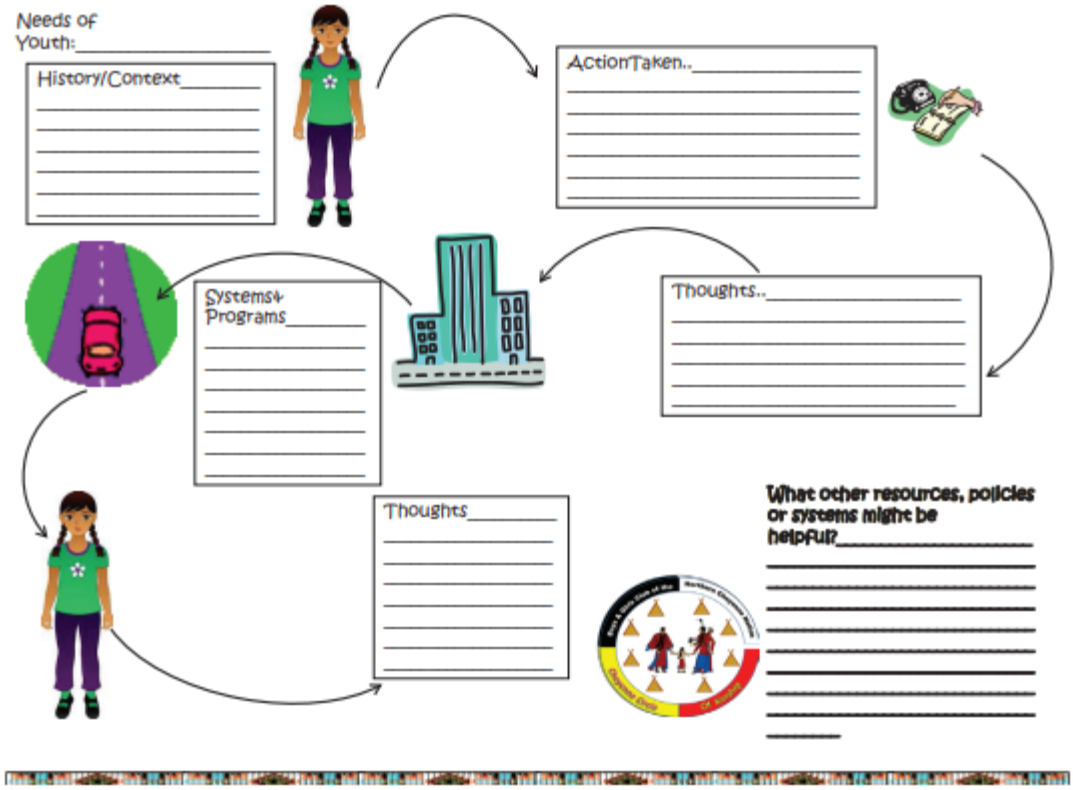
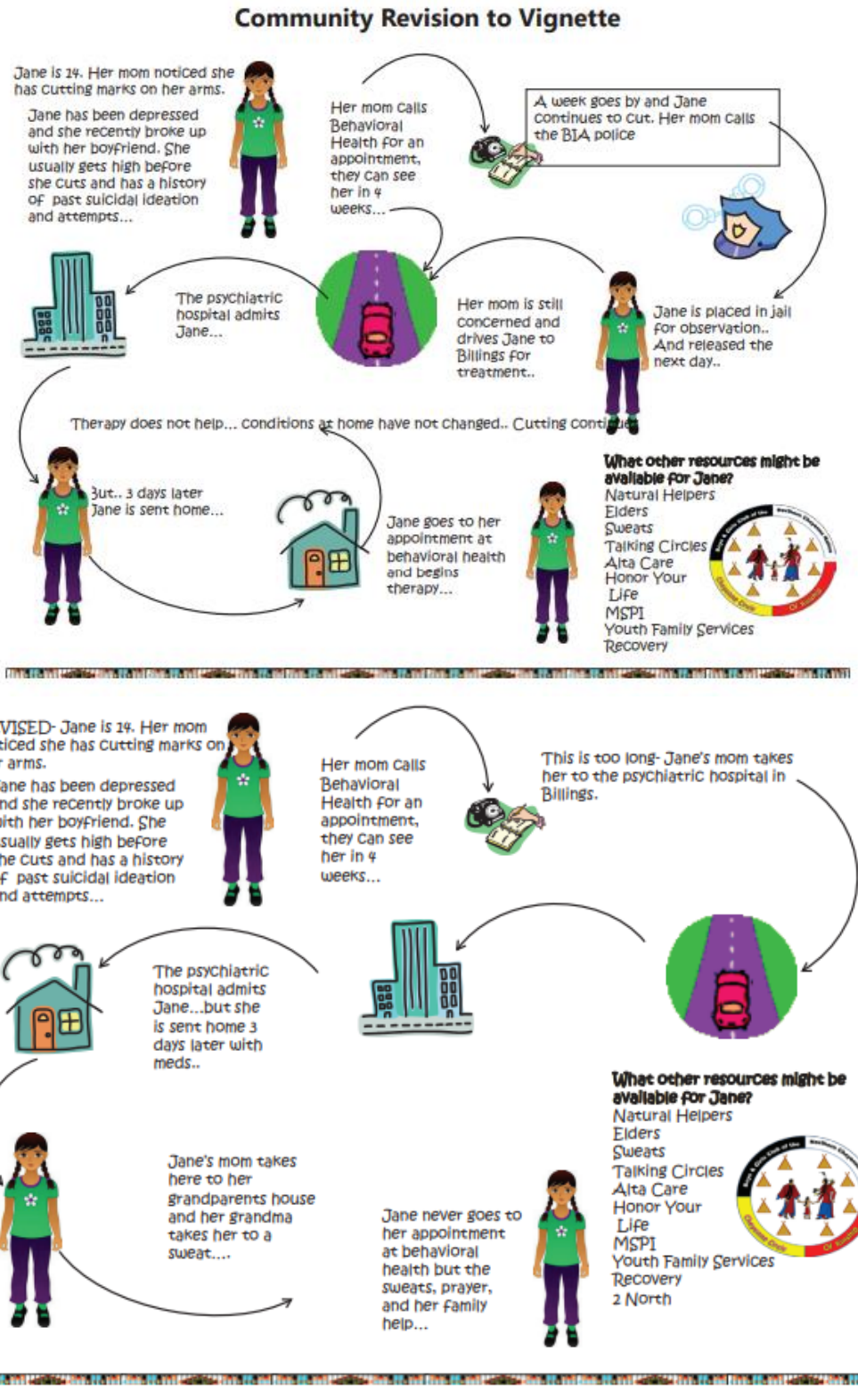
Appendix A
Visual Vignettes

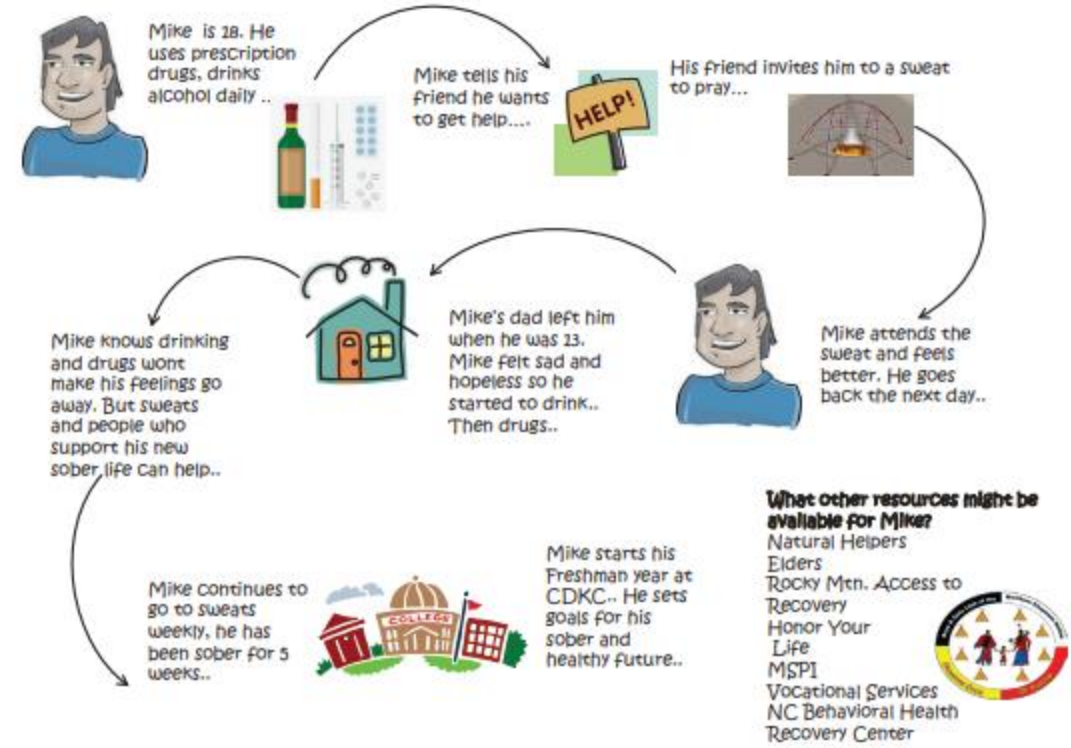
Blank Vignette



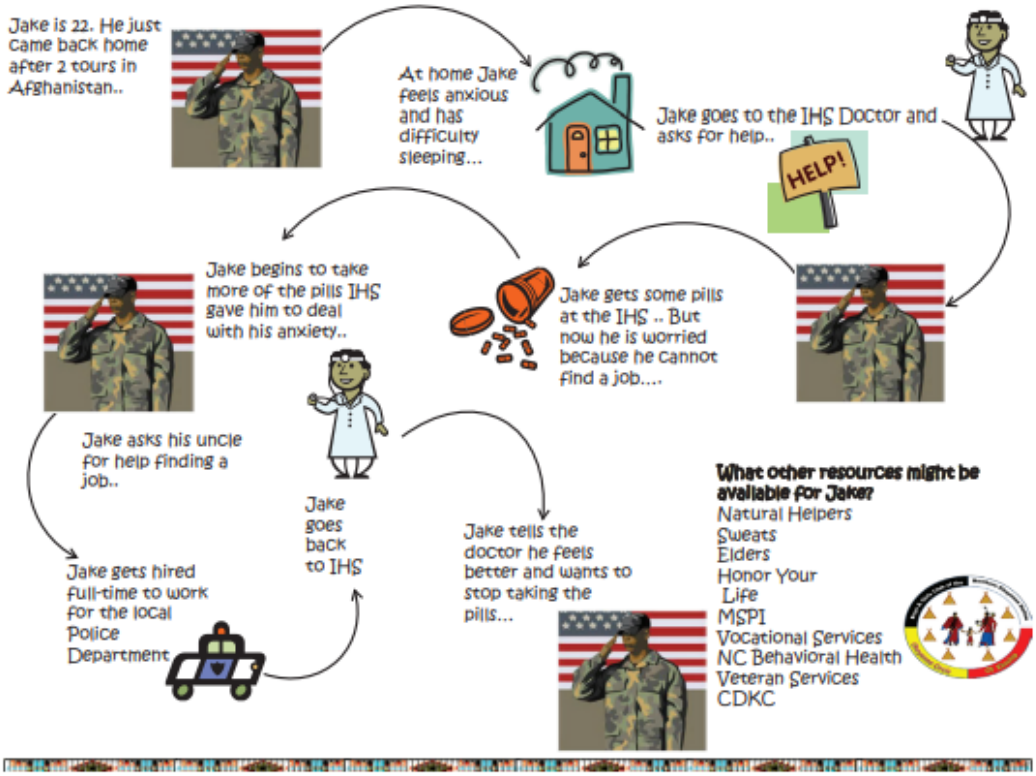


These two vignettes show how a community member changed the process from the first to the revised/ second. During an interview, the community member suggested removing the step where BIA police are called and Jane is placed under observation.

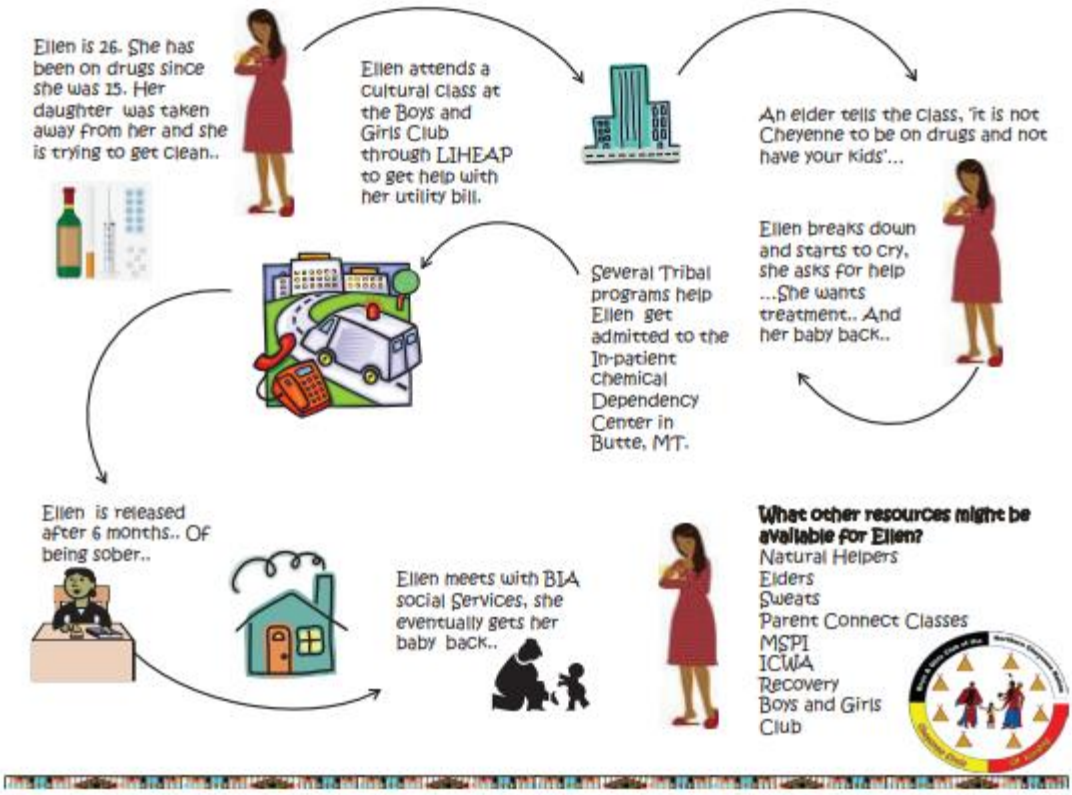
Substance Use



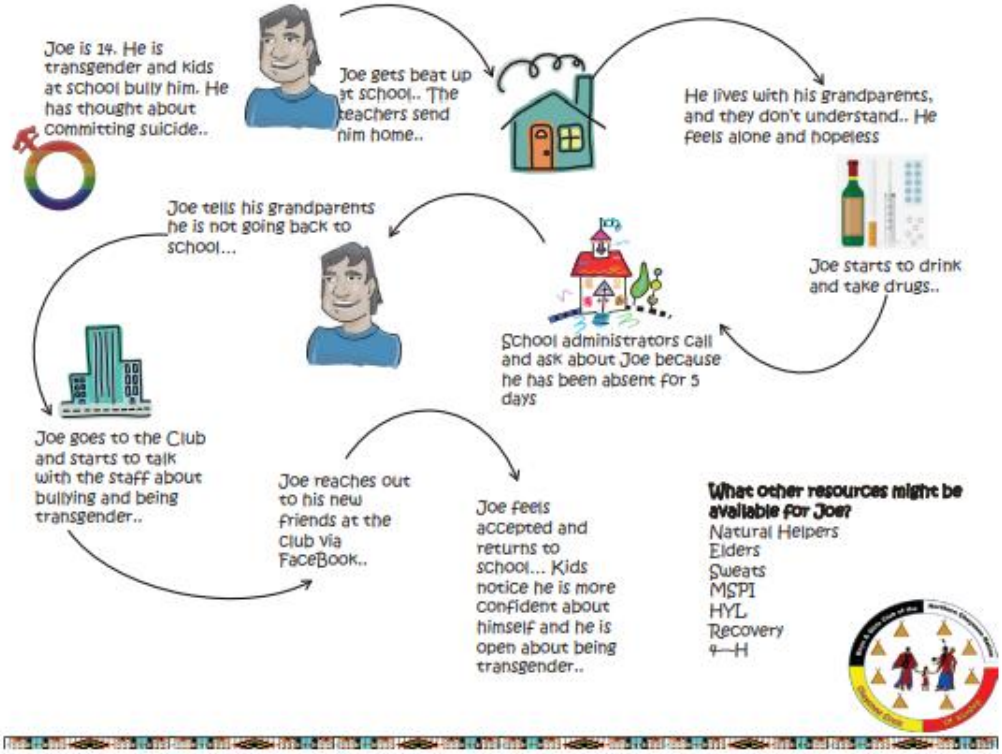
Veteran



Parent



Transgender



Systems of Care

Systems of Care Northern Cheyenne

Educational Support
Materials and supplies for low income families
Parent Connect Classes
Schools

Mental Health
Youth and Family Services Counseling
Youth Dynamics-C
Behavioral Health
Alta Care
Dept. Health & Human Services
Psychiatric Hospitalization-B

Churches
Blessed Sacrament Catholic Church
Morning Star Baptist
Christ the King Catholic Church
Latter Day Saints
Prayer Lodge

Substance Abuse Help
Meth Suicide Prevention for Support
Recovery Center for Treatment
Behavioral Health for Counseling
Youth Dynamics for Counseling-C
Rocky Mountain Tribal Access to Recovery for Treatment-B
In Patient Chemical Dependency Center <18 years
Blessed Sacrament Church 12 Step Program

*C=Colstrip, B=Billings

Food
WIC, TANF, SNAP for Low Income
Commodity Food Program

Shelter & Housing Support
Rose Bud Lodge Shelter for Children
ICWA, Housing Authority, LIHEAP
Housing Assistance Council
Friendship House- B
St. Labre Family Services-Child Residential Care and Clothing
Youth Dynamics for Emergency Shelter
Tumbleweed Runaway Program-B

Recreation & Activities
Boys and Girls Clubs
Circle of Life Youth Group

Juvenile Justice
Second Season
Tribal Courts
BIA
Healing Hearts

Medical Services
IHS Clinic
Sheridan Memorial Hospital
St. Vincent Hospital
Billings Clinic

Abuse
BIA Social Services
Child Family Services-B