



STRENGTHS AND BARRIERS IN IMPLEMENTING THE ACE SCREENING
TOOL IN TRIBAL, URBAN INDIAN, AND RURAL SETTINGS

PREPARED FOR:

ACES AWARE

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&

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www.ACEsAware.org

PREPARED BY:

BECKY GARROW, MPH



Garrow Consulting, LLC
Sacramento, California

www.garrowconsulting.com

(916) 359-9631

becky@garrowconsulting.com

MAUREEN WIMSATT, PHD, MSW



Center for Healthy Children and Communities, Inc.
Sacramento, California

www.centerhcc.org

maureen.wimsatt@centerhcc.org

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Thank you to the following key informants:

Jami Bartgis, PhD

President/CEO

ONE FIRE ASSOCIATES, LLC

Evelyn Eterno, LCSW

Behavioral Health Director

BAKERSFIELD AMERICAN INDIAN
HEALTH PROJECT

Angela Glore, PhD

Executive Director

FIRST 5 DEL NORTE

Britta Guerrero

Chief Executive Officer

SACRAMENTO NATIVE AMERICAN
HEALTH CENTER

Virginia Hedrick, MPH

Executive Director

CALIFORNIA CONSORTIUM FOR
URBAN INDIAN HEALTH

Nicole Hinton

Executive Director

FIRST 5 MODOC

Ryan Howard

Executive Director

OWENS VALLEY CAREER
DEVELOPMENT CENTER

Magdalena Sunshine Serrano, LCSW

Director of Behavioral Health

COMMUNITY HEALTH CENTERS OF
THE CENTRAL COAST, INC.

Erika Eva Tracy

Executive Director

HOOPA TRIBAL EDUCATION
ASSOCIATION

Marc Thibault

Project Director

KERN COUNTY MEDICALLY
VULNERABLE CARE COORDINATION
PROJECT & RESILIENT KERN

Utaka Springer, PhD

Clinical Director, Behavioral Health

NATIVE AMERICAN HEALTH CENTER

PRACTICE PAPER OVERVIEW



INTRODUCTION AND METHODS

The Adverse Childhood Experiences (ACE) Study was originally developed and conducted at Kaiser Permanente in the 1990s. During the study approximately 17,000 patients were asked about ACEs, and responses to these questions were compared to short- and long-term outcomes in health care use and death among individuals in the study.¹ Major findings indicated that higher ACE scores were associated with numerous health and social problems, including higher rates and deaths due to chronic diseases; poorer mental health including higher rates of suicide; substance use and abuse; greater risk for intimate partner violence; and riskier sexual behaviors which can lead to sexually transmitted diseases and unintended pregnancies. Because of this study, interest in childhood trauma and stress and utilization of the ACE screening tool increased. In 2010, the Centers for Disease Control and Prevention began including ACE questions as optional modules within the state-administered Behavioral Risk Factor Surveillance Survey (BRFSS). Since then, implementation has further expanded to including screening for ACEs in medical, social service, and educational settings.

In 2019, Dr. Nadine Burke Harris² was appointed as California's first Surgeon General by Governor Gavin Newsom. In partnership with the Department of Health Care Services, Dr. Burke Harris developed a program called "ACES Aware" to incorporate ACE screenings for children and adults up to age 65 into Medi-Cal (California's Medicaid Program). Effective January 1, 2020, Medi-Cal providers who completed and attested to an ACEs Aware Core Training began receiving payment to conduct non-mandatory ACE screenings utilizing the Pediatric ACEs and Related Life-Events Screener (PEARLS) tool for children ages 0-19 and the original ACE screening tool for adults aged 20 and older.³

Many tribal, urban Indian, and rural clinics have decided not to incorporate the ACE screening tool, and subsequently are either a) not receiving Medi-Cal reimbursement for providing trauma-informed care, or b) not providing trauma-informed care consistently. Relatedly, some agencies have declined Medi-Cal reimbursement for ACE screenings due to a fear of discrimination and policing of vulnerable populations in tribal, urban Indian, and rural settings. Finally, training and Medi-Cal reimbursement may not be worthwhile for clinics that lack referral resources for individuals with high ACE scores.

To better understand strengths and barriers to administering the ACE screening, 12 key informant interviews (KIIs) were conducted via telephone with tribal, urban Indian, and rural organizations in California between October and December 2020. Key informants included clinic directors with decision-making power, providers, and community health workers interacting directly with American Indian/Alaska Native (AIAN) patients and rural community members. Thematic analysis was conducted with Provalis QDA Miner. The KII guide is available in the appendix of this practice paper.

¹ <https://www.cdc.gov/violenceprevention/aces/index.html>

² <https://www.cdc.gov/brfss/index.html>

³ www.acesaware.org

RESULTS

Results of key informant discussions are summarized in the context of major topics that emerged during interviews including four primary areas of strengths and barriers to implementing the ACE screening tool in tribal, urban Indian, and rural settings. These areas (i.e., thematic categories) were: (1) *Screening instrument considerations*; (2) *Infrastructure for screening*; (3) *post-screening treatment and follow-up*; and (4) *cultural distrust and community stigma*. Each of these areas is described in greater detail in the following text, along with accompanying recommendations to facilitate the success of the ACEs Aware initiative.



SCREENING INSTRUMENT CONSIDERATIONS

The ACE screening tool was reported to be helpful in identifying early experiences of patients and community members across tribal, urban Indian, and rural settings. Another strength of the tool is that it increases awareness about trauma and historical trauma.

However, several barriers directly related to the tool were identified by key informants.

does not address resiliency



cannot be administered when a person is in crisis



may be triggering



contains sensitive items



lacks cultural appropriateness



(a) The barrier most emphasized by key informants was that the instrument *does not assess resiliency*, meaning that it helps providers to screen for adverse but not protective factors. This leads to an “out of context” view of a patient or community member, which may limit the applicability of follow-up treatment or referrals, since it does not take a holistic view of the individual into account. Because it does not assess resiliency, it also presents a mixed message about the ACE screening as being a part of treatment, as stated by one key informant: *“I think for the ACEs survey to be used as a healing tool, it should include companion follow-up questions about resiliency, knowing what keeps people well, identifying the sources of strength in their life.”*

(b) Another identified barrier was that the *tool cannot be administered when a person is in crisis*. Key informants indicated that many patients enter a clinic or assessment in a state of mind where it is not appropriate to conduct a screener discussing deeply sensitive, traumatic issues. Within the ACEs Aware initiative, there is no guidance on when to administer the tool, and it is left up to providers to determine if the timing is appropriate. Moreover, if interim crisis services are implemented before the ACE

screening because it is in the best interest(s) of a client, there may also be misalignment between crisis-based treatment planning and ACE screening and treatment planning, causing duplicate treatment assessment and planning efforts.

(c) Outside of crisis situations, the *tool may be triggering* and cause a patient or community member to have adverse reactions to its administration. Key informants stated that some patients and community members have already worked through trauma but asking the screener “digs up an old wound.”

(d) The *tool also contains sensitive items*, with no guidance about how/where to administer for maximum privacy and comfort. Within the telehealth landscape, which is more prevalent in tribal and rural communities and commonplace during the COVID-19 pandemic, a patient may be answering personal questions in the proximity of other family members, colleagues, or even strangers. This can be stressful, embarrassing, and/or stigmatizing to patients and community members:

“The mere asking of ACEs questions can actually cause some of our clients to become a little dysregulated.”

“We had an external organization approach a clinic regarding administering a survey [...] at a community event. Our center declined their request because it included the ACEs questions, and, because the facility would not be able to provide counseling services on site if the participant became upset as a result of completing the survey.”

(e) A final consideration is that the *instrument lacks cultural appropriateness*. Key informants representing tribal and urban Indian settings emphasized that the screening is not implemented within the context of a cultural lesson/teaching and does not include language specific to Native people: It may be conversationally abrupt or culturally inappropriate to introduce the screening without these elements. The tool is accompanied by resources with generic 1-800 numbers for support. However, these resource operators are often unable to provide a culturally informed response in AIAN communities. Finally, the tool assesses experiences and aims for treatment within the individual without focusing on larger community experiences/traumas or healing. In Native culture, community experiences and healing are a priority, sometimes more so than individual experiences.

RECOMMENDATIONS: SCREENING INSTRUMENT

Barrier	Recommendations
<i>does not address resiliency</i>	Assess individual resiliency as well as community strengths and adverse experiences.
<i>lacks cultural appropriateness</i>	<p>Allow for cultural adaptations to the instrument (e.g., adding cultural resiliency questions, being able to describe the tool within a cultural context or story). This will make the instrument more culturally appropriate.</p> <p>Develop culturally appropriate/customizable resources to introduce the screening and accompany its administration. This includes handouts, resource guides, and culturally based referrals and mental health services.</p>
<i>may be triggering; contains sensitive items</i>	Provide guidance on the appropriate setting to administer the tool and who should administer it in case a patient is triggered by its content. This will lessen the triggering nature of the content in the tool.
<i>cannot be administered when a person is in crisis</i>	Allow providers to use their discretion and judgement on when a screener is implemented rather than standardizing its use at intake, which means that it could be administered when a person is not in crisis.

INFRASTRUCTURE FOR SCREENING

Key informants reported being pleased that the ACE screening is eligible for Medi-Cal reimbursement and appreciated not having another “unfunded mandate”. Many indicated that Medi-Cal reimbursement helped facilitate buy-in from administrative staff and board members to participate in the ACEs Aware Initiative. Yet, across tribal, urban Indian, and rural settings, there were infrastructure challenges that hindered ACE screenings.

insufficient time to conduct screening



billing concerns



challenges with workflow



Concerns included:

(a) Many providers reported there was *insufficient time to conduct the screening* during a medical and behavioral health appointment. Some mentioned that there were too many screeners (mandated and non-mandated), which made it hard to prioritize the ACEs assessment. This was particularly true in settings where there are few providers trained in ACEs; there may be non-provider staff members who have the time to conduct the screening, but they are not qualified to administer or discuss the topics in the tool.

(b) There were also *billing concerns* related to the amount of reimbursement, citing the small amount as not being financially motivating enough to complete the screener at many sites. Additionally, sites cannot bill for continued mental health treatment for Medi-Cal patients who receive a “high ACE score” but do not meet criteria for a behavioral health diagnosis, although legislation passed after KII discussions has assisted with treatment reimbursement for individuals without a behavioral health diagnosis.

(c) Key informants further identified *challenges with workflow* within clinic settings. Administrative burden (e.g., scanning forms, disaggregating medical/behavioral health data, incorporating results of screenings into electronic health records) was of concern in already-taxed clinic settings. High levels of staff turnover and compassion fatigue were mentioned, with ACE screenings sometimes negatively impacting providers: *“Just the burden on clinic administration – to be able to bill for the ACE screening and setting up all the systems to capture and report the data safely and responsibly, is daunting.”* Another challenge was patients receiving community screenings without clinic staff knowing the results, leading to duplication of efforts and patient over-assessment.

RECOMMENDATIONS: SCREENING INFRASTRUCTURE

Barrier	Recommendations
<i>insufficient time to conduct screening</i>	<p>Whenever possible, duplicate screening and assessment workflows being utilized by other state-funded systems, such as CalFresh, translation services, etc. This will maximize time spent on assessments without adding screening burden to providers.</p> <p>Promote strategies to reduce the chances of patients and community members being screened multiple times across settings. This may involve restricting community screenings or investing in collaborative data entry tools.</p>
<i>billing concerns</i>	<p>Reimburse sites at higher rates for conducting multiple screenings, including ACE screening, in one visit rather than requiring patients to attend multiple appointments.</p>
<i>challenges with workflow</i>	<p>Provide logistical guidance (i.e., technical assistance, trainings, toolkits) about incorporating ACEs into clinic workflows, including how to build into electronic health record systems, appropriate data storage and security, and scanning and reporting to the ACEs Aware initiative. This will eliminate the need for sites to “recreate the wheel” in developing/adapting workflows.</p>

POST-SCREENING TREATMENT AND FOLLOW-UP

Many AIAN patients have established, trusted, culturally appropriate relationships with medical providers at Tribal Health Programs and/or Urban Indian Health Centers. Additionally, reduced or free cost of behavior health services through the Indian Health Service and other grant-funded initiatives, and institutionalized “warm handoffs” between medical and behavioral health departments have helped eliminate several barriers for AIAN seeking behavioral health services.

However, for rural agencies and AIAN receiving care within and beyond tribal and urban Indian clinics, several concerns about post-screening treatment and follow-up were identified.

lack of treatment and follow-up resources



screening ≠ need for treatment



treatment approach is not standardized



treatment approach is not culturally relevant



Concerns included:

(a) Across all interviews, key informants cited a *lack of treatment and follow-up resources* as one concern in utilizing the ACE screening, even though it may be useful in identifying treatment needs.

In many tribal and rural areas, there is a lack of health providers and educators, as well as other resources that help address social determinants of health like racism, food insecurity, illiteracy, limited access to technology, and transportation barriers. Some patients and community members must drive several hours to receive treatment or attend a follow-up appointment. Across all settings, access to specialty care may be limited, requiring lengthy waiting periods of six months or more to see a Medi-Cal approved psychiatrist for behavioral health. Key informants highlighted ethical concerns in screening for ACEs and identifying needs that a provider cannot readily treat or address: *“The more we screen, the more we get answers, the more we have a responsibility to*

provide support and interventions” and “It is not ethical to screen someone and then not have anywhere to send them for support.”

Telehealth did not readily eliminate this barrier as populations most in need of ACEs services had limited access to and understanding of digital platforms. For example, one clinic was interested in having “...patients input [ACEs] data in a web-based data portal - but this approach would eliminate the participation of patients with limited digital capacity.”

(b) Some key informants indicated that a *screening does not necessarily mean there is a need for treatment*, saying, “What’s interesting in the hand off is that the client is assumed to need behavioral health support.”

(c) Assuming there is a potential need for treatment and individuals can find treatment nearby, there are other concerns. First, many patients lack insurance options that will cover behavior health services or cover these services at a rate that is affordable. More broadly, however, *the ACEs Aware treatment approach is not standardized*. A lack of standardization means that providers do not know which score necessitates what specific treatment. They also do not have training or confidence in providing trauma-informed care at varying levels of ACE scores. A lack of “next steps” or “what to do” also highlights another area of concern, which is that ACEs Aware does not explicitly promote or fund culture-based treatments for specific ACE scores within diverse groups. The lack of specificity and inclusiveness both lend to tribal, urban Indian, and rural providers and community organizations being unsure of whether ACE screening is relevant for their population. “The big question is, ‘So what? We do the screening- what now? We see high ACE scores. What now? What do we do with this information?’”

(d) In tribal and urban Indian settings, there is an additional layer of concern with treatment and follow-up, as *the ACEs Aware treatment approach is not culturally relevant*. Many patients already have trusted providers and medical supports within tribal and urban Indian clinics; however, the ACE screening and treatments may require these clinics to refer AIAN people to other non-Native providers like specialists with limited understanding of Native peoples. Worse may be a potential referral to government-sponsored mental health professionals, such as a county behavioral health worker. There is a history of abuse with government-sponsored health services, and many AIAN do not trust and will not attend appointments with providers working on behalf of an outside government or entity. County officials also demonstrated a lack of confidence in providing services on or near a tribal reservation or to AIAN people due to a lack of cultural knowledge or unfamiliarity with the tribe, tribal health center, or urban Indian clinic.

“[...] people here use [the tribal clinic] as their primary point of medical care. Part of that is cost, part of that is a cultural connection. Like anywhere else, there is a long history of discrimination and genocide here, and it is fresh in people’s minds. We have people whose parents were taken to boarding schools against their wills – there’s that memory of what government means – that is still alive in this county.”

“[Staff] may not feel confident if they’re responding to a call on a reservation – this makes it harder – they don’t have experience in that community. No established relationships. They’re reluctant to engage, so they don’t. Not because of a lack of desire, but a lack of an entry point or relationship.”

RECOMMENDATIONS: POST-SCREENING TREATMENT AND FOLLOW-UP

Barrier	Recommendations
<p>lack of treatment and follow-up resources</p>	<p>Fund rural resources in behavioral health before overlaying ACE screenings on top of limited resource system. This will limit staff turnover and prevent fatigue among existing providers.</p> <p>Pay for post-screening health navigators to assist individuals from rural settings access appropriate treatment and follow-up services. This will assist in the identification of as many follow-up resources as possible.</p> <p>Fund statewide digital literacy training programs and device distribution so that all can access needed healthcare.</p>
<p>screening ≠ need for treatment</p>	<p>Create guidelines for providers about what would require behavioral health treatment beyond a behavioral health diagnosis. Identify warning signs that might necessitate treatment regardless of ACE score.</p>
<p>treatment approach is not standardized</p>	<p>Standardize treatment for ACEs, including trauma-informed, culture-based interventions for individuals with specific scores. Pay for providers to receive training in these approaches.</p>
<p>treatment approach is not culturally relevant</p>	<p>Incentivize sites that provide holistic care in one location. For example, train and fund trusted providers in tribal and urban Indian health centers to conduct screenings and follow-up treatment all in one location. This will ensure treatment locations are comfortable/familiar for patients and services are grounded in culture and culturally appropriate traditions.</p>

CULTURAL DISTRUST AND COMMUNITY STIGMA

Stakeholders agreed about the importance of assessing and recognizing trauma, particularly in communities of color and rural areas. Many interviewed for this practice paper expressed overshadowing concerns about potential cultural distrust and community stigma associated with ACEs, particularly when it is known that most diverse communities will likely “screen higher” for past adverse events. Stakeholders indicated that these concerns should be addressed for ACEs Aware to be successful in tribal, urban Indian, and rural settings.

no apparent purpose for ACE screening



potential magnification of communities



cultural misunderstandings & stigma/stereotyping



Community and cultural concerns included:

(a) *No apparent purpose for ACE screening* beyond reimbursement because there is no formalized, statewide plan for post-screening treatment or intervention.

“If they are looking to prove that low-income people of color are struggling, we don’t need [the ACE screener] to identify that.”

“I want to understand how the data is being used. Statewide? Representing all AIAN? Do areas with bad scores end up with additional funding?”

“ACE scores are between 1 and 10. I don’t want kids walking around with an assigned number, having that determine how they see themselves, how they self-identify.”

(b) *Potential magnification of communities* already overserved by police and over-reported in government systems.

Parents are... being evaluated by someone who doesn’t understand them or their [culture/community]. Child abuse is not hard to diagnose or screen,

but there are a lot of cultural incompetencies between the community and the folks who are doing the screening and I am concerned about that.”

“We can look at any zip code and learn more about where the adverse experiences are – I feel the ACEs tool holds a magnifying glass to these communities, who are already overserved by police... our clinic is a safe place, and we don’t want to penalize people because they don’t have the tools they need to be successful.”

“There’s a long history of AIAN having decisions taken out of their hands, labeled or categorized, distressed with predominant cultural authority figures and systems.”

(c) *Cultural misunderstanding and stigma/stereotyping* by providers and community administrators of ACE screenings, particularly in tribal and rural areas where there is a lack of anonymity.

“We have a rancher, strong, rural mentality. Folks don’t want to seem weak or like they’re not able to cope.”

“Historical trauma creates sensitivity around identification.”

“We see people who are undocumented, and there is a lot of sensitivity at being identified.”

“[...] patients that call 1-800 numbers [are] reaching someone who is not AIAN, not culturally competent, and cannot meet their need with a culturally informed response.”

“I really feel like the home visiting program for the tribal community would be the best way. Sometimes when [people] go to the doctor, they feel judged.”

RECOMMENDATIONS: CULTURAL DISTRUST AND COMMUNITY STIGMA

Barrier	Recommendations
<p>no apparent purpose for ACE screening</p>	<p>Reach consensus on the purpose of ACEs Aware, whether it is for screening or treatment or both. Publicize this rationale using campaigns tailored for tribal, urban Indian, and rural settings. This will help clarify the purpose for ACE screening.</p>
<p>potential magnification of communities</p>	<p>Whenever possible, use data from communities for population-level health education and intervention. Do not utilize data from individuals which could lead to increase magnification or “policing” of communities/</p> <p>Fund trusted cultural and community leaders to provide ACEs education outreach, screening, and treatment in various settings including the clinic and at home. This will reduce magnification of communities in clinical settings and increase comfort in providing information about trauma and/or behavioral health to government entities.</p>
<p>cultural misunderstandings & stigma/stereotyping</p>	<p>Engage in listening sessions/conversations about trauma with people from communities of color and rural communities. Adapt the ACE screening model based on feedback obtained during these sessions. This will reduce cultural misunderstandings and inadvertent stigma/stereotyping by providers.</p>

NEXT STEPS

As part of the peer review process for this practice paper, we engaged the ACEs Aware Initiative to discuss findings. The ACEs Aware leadership team expressed interest and commitment to partnering with Tribal, urban Indian, and rural communities to develop ACEs Aware materials tailored to cultural and regional practice needs. The goal of materials developed through the ACEs Aware initiative is to advance the understanding and effectiveness of strategies for addressing ACEs, treating toxic stress, and providing culturally appropriate trauma-informed care. We look forward to working in partnership with ACEs Aware to address the findings and concerns outlined in this paper.

KEY INFORMANT INTERVIEW GUIDE

Key Informant:

Clinic/Practice:

Date of Interview:

INTRO TEXT for CALL

Hi {Name},

Thank you again for taking the time to speak with me today. As we discussed via email, the goal of our project is to better understand barriers that rural, tribal, and urban Indian communities in California may face with implementing the ACE screening tool. I'm excited to learn more about your experiences with this topic.

As a reminder, your name and organization will not be associated with any of your answers and your responses will be combined and summarized with the other key informants.

Is it OK if I record this call? The recording will be deleted at the end of the project (1 year from now) and will be used only to verify the notes I'm taking during the call and to capture any important quotes accurately.

Do you have any questions for me before we begin?

Questions

1. I'd like to learn a little more about you and your clinic/practice/program.
 - a. *Please describe to me the populations served by your clinic/practice/program and the types of services you provide.*
 - b. *Do you consider the community/communities you serve to be rural, urban, or both?*
 - c. *What is your job title?*

2. Do you identify as American Indian or Alaska Native? a. Yes / b. No

Now, I'd like to talk about the Adverse Childhood Experiences (ACE) screening tool.

3. To what extent does your clinic **routinely** administer the ACE screening tool?
Probes: Is the tool administered to all patients? Most? Case-by-case/rarely? Never?

[If the ACE screening tool is NOT administered:]

4. Tell me why you/your clinic/your practice is not administering the tool.

[If the ACE screening tool is administered (ever):]

5. How does your Tribe/program/county administer the ACE screening tool?
 - a. *Who completes the form?*
 - b. *Is the screening form Identified or De-Identified (PEARLS)?*
 - c. *Are there any procedures for who can be in the room when the tool is being completed?*
 - d. *Are there different procedures for administering the tool based on the age or gender of the patient?*
 - e. *Are there other factors that impact how (or if) the tool is administered?*

[ALL]

6. To what extent do you feel the ACE screening tool should be used for assessing and treating individuals?
 - a. *Do you regard the tool as a screening tool? Diagnostic tool?*
 - b. *Do you feel that the ACE screening tool should be used to inform treatment or services for individual patients? Please describe.*
7. Now I'd like to learn more about what barriers if any, you or your colleagues face when screening for ACEs in your clinic.
 - a. *Do you feel there are any concerns with identification related to the ACE screening, particularly for tribal/rural populations?*
 - b. *To what extent do you feel that American Indian and Alaska Native patients may be afraid to complete the ACE screening? Please describe.*
 - c. *Do you feel that screening for ACEs poses any risk(s) to your patients or your community?*

- d. What concerns, if any, do you have regarding discrimination? Policing?
Other concerns?*
 - e. Are there concerns with the way the ACE screening is administered? The way that data is collected and/or shared?*
 - f. Are there concerns with the amount of time it takes to administer the ACE screening?*
8. Are there concerns about providing or referring patients to appropriate services AFTER an ACE screening is provided? (Probes: lack of referrals or resources in community, lack of trust, etc.)
9. To what extent does receiving Medi-Cal reimbursement influence your clinic's practices regarding administering the ACE screening tool?

[If the ACE screening tool is NOT administered:]

10. How does the lack of Medi-Cal reimbursement impact your clinic/practice?

[ALL]

11. What processes or government changes would need to occur for you to more comfortably utilize ACEs to screen within your Tribe/health program/county?
12. What, specifically, is needed for the ACEs Aware program to be successful with American Indian and Alaska Native patients?
13. Is there anything we haven't talked about or that you would like to add to any of your earlier answers?
14. Our team plans to present the results of these key informant interviews, including findings and recommendations, at a webinar in 2021. Do you have any recommendations on who should be invited to this presentation to provide discourse on this topic?