Result from Fetal Alcohol Spectrum Disorders Focus Groups

REPORT

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Alliance

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Prepared by ACET, Inc.

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Executive Summary

Proof Alliance is a nonprofit organization dedicated to preventing Prenatal Alcohol Exposure (PAE) and supporting individuals and families impacted by Fetal Alcohol Spectrum Disorders (FASD). In Spring 2025, Proof Alliance partnered with ACET to conduct a series of focus groups to assess community awareness, perceptions, and information pathways related to PAE & FASD. The purpose of this initiative was to better understand how community members—including birthing persons, those connected to them, and community leaders or providers—receive, interpret, and engage with information about PAE & FASD and children's health, while also exploring attitudes toward alcohol use during pregnancy and within the broader cultural context.

To ensure cultural and ethnic diversity, the focus groups engaged participants from Black/African American, Latino/a/Latinx/Latine, and Somali communities. A total of 30 individuals participated in the focus groups across three of these groups. ACET led the design, facilitation, and analysis of the focus groups. ACET collaborated closely with two community partner organizations, REBOUND, Inc., and HACER, and one Somali community leader, Bureeqo Dahir, who supported the recruitment of participants. ACET's expertise in culturally responsive engagement and qualitative research was instrumental in shaping a process that centered on inclusion, trust, and respectful dialogue.

While participant responses were nuanced and reflected a wide range of lived experiences, several shared themes emerged across the focus groups. These findings reveal consistent gaps in awareness, access to information, and understanding of prenatal alcohol exposure and PAE & FASD, as well as insights into how messaging and support services might be strengthened within culturally specific communities. Some of the findings were:

- Understanding the effects of PAE and FASD on children and families varies across racial identities.
- There is a persistent misconception of alcohol use during pregnancy (e.g, a small glass of wine is okay).
- Alcohol is normalized in Western culture and in most families.

- Most community members primarily get their information about children's health from social media (e.g., TikTok).
- "Boots on the ground" community engagement is considered the most effective way to connect with the community.

This report highlights opportunities for Proof Alliance to continue building meaningful, collaborative relationships with the community partners involved in this project, as well as with additional organizations interested in learning more about and supporting FASD-related work. These findings offer a foundation for deeper engagement, culturally relevant outreach, and sustained community education across the Twin Cities and Greater Minnesota.

Purpose and Background

Fetal Alcohol Spectrum Disorders (FASD) is a preventable condition caused by Prenatal Alcohol Exposure (PAE), yet awareness is inconsistent across many communities. The goal of this project was to engage diverse populations to capture community insights and identify knowledge gaps. In addition, we discussed which communication channels the community uses to receive and engage with information about alcohol and children's health. With this in mind, we outlined three key areas for the focus group questions.

Awareness of PAE & FASD

Awareness refers to the level of knowledge and understanding that community members have about PAE and FASD, including its causes, effects, and how it can be prevented.

Community Perspectives on Alcohol Use

Community perspectives capture the attitudes, beliefs, and cultural viewpoints that shape how individuals and communities think about PAE and the effects of FASD. These views are influenced by personal experiences, cultural norms, faith traditions, and the stigma associated with discussing alcohol use, particularly concerning parenting and pregnancy.

Community Information on Children's Health

This includes how community members access and receive information related to PAE and FASD and children's health more broadly. It encompasses trusted sources (such as community leaders, faith-based figures, or social media), preferred communication methods, language accessibility, and the overall availability and clarity of health education in the community.

Methods

Community Partner & Participant Recruitment

Proof Alliance was interested in hearing from four different communities: Black/African American, Latino/a/Latinx/Latine, Somali, and Hmong. ACET reached out to partners from these communities to support the facilitation and recruitment for the focus groups. ACET connected with several Hmong community partners, and although the community partners were interested in the topic, we were unable to bring them to the table. As with most culturally diverse communities, the entrance to challenging conversations about taboo topics lies in building trust between organizations and communities and having a trusted community member open the door to the conversation. The three community partners who recruited participants and hosted the focus groups have deep ties to the communities they serve and were open to the opportunity to have this discussion.

REBOUND, Inc. has the tools and expertise to meet the needs of Black/African American kids and families. Rebound, Inc. works to establish programs in the Black/African American community and works for the betterment of the community.

HACER's (Hispanic Advocacy and Community Empowerment through Research) mission is to engage Latino Minnesotans through research, evaluation, and community action to promote equitable representation at all levels of institutional decisions and policy change.

Bureeqo Dahir has worked in early childhood education for over 10 years, bringing a wealth of experience to the table. She is passionate about building strong relationships with providers, believing that these relationships are critical to the success of early education programs and ultimately empower children to thrive. Bureeqo serves as a bilingual early childhood coach at the Center of Inclusive Childcare, providing support focused on the successful inclusion of children with special needs or challenging behaviors, implementing health and safety best practices, and/or supporting the unique needs of infants and toddlers.

Participant Demographics

ACET created a registration form that all participants were required to complete. The registration form asked for name, race/ethnicity, and email. They were also asked to identify one or more of four key groups that describe how they see themselves within the parameters of pregnancy and their roles in the racial/ethnic community. As part of defining the four key groups ACET aimed to engage within the communities, the following identities were established:

- **Birthing Persons**: Individuals who are currently pregnant or have previously given birth, representing a central group in FASD prevention efforts.
- **Individuals Connected to Birthing Persons**: Partners, family members, or caregivers who play a role in influencing decisions related to alcohol use during pregnancy.
- **Community Leaders/Advisors**: Influential community members—such as faith leaders or neighborhood advocates—who help shape public attitudes and increase awareness about FASD.
- **Providers Working Within the Community**: Professionals such as healthcare workers, social workers, and educators who play a direct role in prevention efforts and in connecting individuals to necessary resources.

Participants often identified with more than one group based on their roles in the community, as shown in the table below.

Community	# of Participants	Birthing Persons	Connected to Birthing Persons	Community Leaders	Providers in the Community
Black / African-American	10	70%	10%	10%	90%
Latino / a / Latine / Latinx*	10	90%	100%	40%	20%
Somali	10	10%	100%	70%	90%

** One individual in this group identified themselves as Persian (Middle Eastern)*

Data Collection and Data Analysis

ACET conducted two focus groups in person and one virtually. The Somali focus group was conducted in Somali, and the translator verbally translated the focus group participants' reflections into English during the focus group. At the beginning of each focus group, ACET asked participants for permission to record. One group did not grant permission to record. We took written notes during all three focus groups and transcribed the two recordings. These transcriptions, along with notes taken during the focus groups, were used in the analysis. ACET organized the data by assigning color codes to responses from each community to highlight perceptions and identify patterns, similarities, and differences.

Key Findings

The following key findings capture the perspectives shared by focus group participants on FASD, alcohol use, and children's health. Representing a range of community voices—including birthing persons, individuals connected to birthing persons, community leaders, and providers in the community—these insights offer a nuanced understanding of how individuals receive, interpret, and act on information related to FASD. Participants contributed personal stories, cultural viewpoints, and reflections on both challenges and opportunities for prevention, education, and support. The emerging themes highlight community strengths while also pointing to critical gaps where enhanced outreach, accessible resources, and culturally responsive messaging are essential.

Below, we share key findings in three sections: **Awareness of PAE & FASD; Community Perspectives on Alcohol Use** and **Community Information on Children's Health**. We begin each section with a synthesis of findings across the three focus groups, naming when communities differed in what they shared. We then dive more deeply into how each community answered our questions, providing nuances and participants' quotations that help contextualize the key findings.

Awareness of PAE & FASD

We first wanted to understand whether participants had heard the terms Prenatal Alcohol Exposure (PAE) or Fetal Alcohol Spectrum Disorders (FASD), as well as the participants' awareness of Proof Alliance and the work the organization is doing in Minnesota. Two focus groups (Black/African American & Latino/a/Latinx/Latine) had specifically heard the term Fetal Alcohol Spectrum Disorders. The Black/African American focus group had **detailed knowledge** about symptoms and long-term effects of FASD and its connection to PAE. Some participants in the Latino/a/Latinx/Latine community confused FASD with other developmental or behavioral disorders, and most of those individuals related the symptoms of FASD specifically to those of ADHD or Autism. The first two questions in this section were a challenge for the Somali participants, as alcohol is prohibited in Islam.

1. ***Before today, had you heard of Proof Alliance?***

    a. ***If yes: Have you heard about the work Proof Alliance does? If so, where did you first learn about it? How did you feel about it when you first heard?***

Across the three identity groups, no one had heard of Proof Alliance or the work that Proof Alliance does in Minnesota.

2. ***Before today, had you heard of Prenatal Alcohol Exposure (PAE) or Fetal Alcohol Spectrum Disorders (FASD)?***
    a. ***If no: Thinking about alcohol use in your community, which thoughts or images come to mind first?***
    b. ***Hearing the phrase 'a child affected by alcohol before birth' brings up which thoughts or associations for you?***

Black/African-American: All participants within the Black/African American focus group had heard of PAE and FASD. Hearing the phrase 'a child affected by alcohol before birth' brought up associations of addiction and disability. Their discussion was related mostly to cognitive and behavioral issues that show up in early childhood and continue throughout adult life. While they recognized that there are other determinants, such as predominant facial features as indicators of FASD, they also discussed the fear of the involvement of Child Protective Services within a birthing parent's life as possibly one of the reasons children are misdiagnosed with Autism or ADHD.

Latino/a/Latinx/Latine: All were aware of FASD. They recognized FASD as a health condition that affects babies due to alcohol exposure during pregnancy and noted the impact it can have on both the child and the mother.

Somali: Somali participants expressed that they did not know individuals in their community who consumed alcohol.

- *"I don't know someone who consumes alcohol, and I have never seen."*

Community Perspectives on Alcohol Use

Next, two of the three focus groups talked about alcohol use from the perspective of adult and young adult consumption rather than about birthing people and infants/children, and the effects of FASD on their lived experience. Participants discussed the misconception that small amounts of alcohol are often seen as less detrimental to birthing parents while pregnant (e.g. glass of wine vs. shots of hard alcohol). Participants described alcohol use as normalized and, in some cases, celebrated within community events and gatherings. While most **acknowledged the risks of drinking during pregnancy**, a few expressed uncertainty or cited conflicting messages they had heard in the past.

1. ***How common do you perceive alcohol use to be within your community?***

Black/African-American: The Black/African American participants felt alcohol use was very common in their community; however, they felt it was less common amongst birthing people who know they are pregnant. They also noted that they saw birthing persons in their 20s and 30s who drink more than elders. They discussed addiction to both alcohol and other substances that may contribute to unplanned pregnancies and an avoidance of prenatal care. They also discussed the fact that the alcohol industry hasn't had any legal cases, so there aren't as many "warning signs" about alcohol as nicotine.

- *"I feel [it's] less common [alcohol use among pregnant people] because I feel like that's something that people would speak up more about. […] when I think about people that drink while pregnant, they've already been heavily in the alcoholism addiction, and the pregnancy wasn't something that was planned… but someone who's willing and able and in their right mind and stuff doesn't really drink while pregnant."*

- *"…Nobody has sued the alcohol industry yet, so there's not the same level of education out there. The tobacco industry got sued… and then there was all these commercials and classes and stuff about the negative impacts of cigarettes. Even though they were still legal,*

people knew that bad things could happen, but that's not happening the same way with alcohol, and there's not warning labels on the bottle…"

Latino/a/Latinx/Latine: One participant noted that alcohol use is seen as common in their community; they noted that other communities (Native American) have a lot of challenges around alcohol use. They also observed that in their community, men tend to consume more alcohol than women, and that often alcohol use is linked to drug use. The participants also see alcoholism as generational, with older generations being more susceptible to alcohol abuse than younger people. There is a common perception that a small amount of alcohol, such as a glass of wine, won't harm the baby during pregnancy. This belief contributes to continued alcohol use during pregnancy.

Somali: Somali participants felt unsure how common alcohol use is in their community

- *"I've heard about it, but I don't really have much knowledge about it."*

2. ***Are there cultural, spiritual, or religious values that have influenced your views about alcohol use?***

Black/African-American: All participants described their first time being exposed to alcohol as through family social events and in church social events. However, most participants discussed being warned against alcohol by their parents and family.

- *"…[My views about alcohol use] definitely coincide with my family. My family has always taught us to not be addicted to anything, and so, teaching us about alcohol and drugs early, at an early age kind of helps."*
- *"[My views about alcohol use] was heavily influenced on both sides of my family. My daddy probably drunk right now, and I'm not being funny. So I just took the measure of being more cautious. I drink a lot less now just because I realized my social drinking was kind of everyday glass of wine."*

Latino/a/Latinx/Latine: Some participants said that their first taste of alcohol was during communion, but most pointed out that alcohol use was unacceptable outside of that religious ritual. They did talk about differences in alcohol use between men and women. They said that many men in their community give alcohol to their sons as a "rite of passage." Some reflected that while growing up, alcohol use, such as taking a sip of beer, was normalized and even seen as humorous within their families, which shaped a more casual attitude towards drinking. One participant mentioned growing up in a household where alcohol use was not accepted, and emphasized the importance of getting to the root cause of alcohol, whether it is cultural, emotional, or environmental.

- *"...as a Christian, drinking was strongly discouraged and considered unacceptable..."*

Somali: The participants acknowledged that within Islam, alcohol is prohibited, and this is one of the reasons why they don't know much about alcohol use within the community. When asked about community conversations around alcohol use—particularly given its easy accessibility in the U.S.—participants emphasized that alcohol remains a stigmatized topic. They noted that community organizations often struggle to engage individuals who have been marginalized due to alcohol use. Additionally, they explained that cultural differences play a role: in the U.S., the expectation of autonomy at age 18 often leads families to distance themselves from their adult children, which contrasts with the more collective family structure they experienced in Somalia. There are also not many community organizations that work with substance and alcohol abuse that are accessible to families.

- *"Yes, in our home country, there was no alcohol being made. Our religion kept us away from it."*
- *"There's a lot of problems in the community. It's a stigma in the community. They [people who use alcohol] can't come to the community [about that issue], that's why they are homeless, because the community won't take them in."*

3. ***Have you or someone you know been affected by FASD? If so, what kind of***

challenges did you/they experience?

Black/African-American: Participants discussed members of their family who have been affected by FASD, specifically, a range of social and behavioral challenges linked to FASD, including aggression, impulsivity, and emotional regulation issues. Additionally, in their varied work through REBOUND, Inc. and other spaces (K-12 education, social work, probation, etc.), they engage with young people who are affected by FASD.

- *"I'm just saying some of the people I've worked with [are]… very reactive, don't have the cognitive skills of impulse controls. The functioning is a little either delayed, or it's not fully there."*
- *"I had a scholar. This was when he was in kindergarten… As fast as he got angry, he would instantly want reassurance that he's still loved, like real fast. He would tear up. He threw a chair in my head."*

Latino/a/Latinx/Latine: One participant shared that several of her cousins are affected by FASD. Both mothers and fathers used to drink, though it's unclear if the mothers drank during pregnancy. Many of the parents passed away in their 50s, and some of their children died in their 30s. One cousin has cirrhosis, and another is awaiting a liver transplant. A participant recalled caring for a baby whose mother drank beer during pregnancy. She wondered whether the baby's constant crying could have been a result of PAE.

- *"I've heard from family that, 'I got my kids drunk.' [Family members think it's] something funny or something to do."*
- *"Drinking in a Pentecostal church…is a big no-no…No drinking on either side of the family."*

Somali: The participants described having difficulty identifying FASD.

- *"…It's very hard for us to know if a child has a disorder, so it's very hard for [families] to identify [children] as [having FASD]."*

4. ***How have families in your community supported children with FASD?***

Black/African-American: They pointed out that there is not a lot of support in the community for birthing parents or children because of stigma and blame, even though alcohol is not as stigmatized as other drugs. They discussed the challenges young people face when they are put into foster care due to their parents' addiction. They believed that behavioral, mental, and emotional issues that may be present due to FASD are magnified by the process of the foster care system. The young people, they noted, are bouncing from house to house without any emotional and psychological support to help them navigate their complicated feelings and thoughts.

- *"Well, one of my foster daughters, she went from house to house to house to house until [she aged out]."*
- *"...[an individual on] my caseload bounced, bounced, bounced until he ended up in prison."*
- *"It just depends so much on self-disclosure of what was going on during pregnancy that there's, I think, probably more people in our community that are struggling than we know about."*

Latino/a/Latinx/Latine: The participants pointed out that social media play a role in shaping perceptions. When children with challenges are posted online, the focus often shifts to blaming the mother. They believed this stigma could discourage families from seeking help and support. In some cases, the authorities may need to get involved, especially if there are concerns about the child's well-being. They said that there is often a lack of knowledge about FASD in the community, which can lead to inaction. One participant mentioned that due to cultural superstitions, people may avoid addressing the issue directly. There was also a discussion about misconceptions, such as whether doctors can force decisions like abortion, which reflects a need for more education and accurate information within the community.

- *"A lack of knowledge, and I don't think people know anything about it. We are superstitious people; the evil eye. We don't know how bad it is to drink when you're pregnant..."*

Somali: Participants discussed that in the past, people would pray for children and families who were affected by a variety of disabilities. Today, places are slowly opening up that help families navigate those challenges, even when discussing alcohol is still a stigma.

- *"The parents can't really do much, but as a community, we work with the youth. It's not just alcohol—they're dealing with all kinds of things. They're hanging out on the streets using all kind[s] of substances, and they don't have housing. These kids are truly struggling."*

5. ***What kinds of support or services have you seen in your community for people who struggle with alcohol use?***

Black/African-American: The participants discussed various well-known formal and informal programs, such as Alcoholics Anonymous (AA) and peer conversations. One of the things they noted is that many people who struggle with alcohol use are "functional," so if those individuals go to an AA meeting and they hear of someone who has "hit rock bottom," it's easy to dismiss. They explained that people need to hear from folks who are in their socio-economic situation and how they managed to be functional while still being an alcoholic. They pointed out that most services are preventative rather than taking a harm reduction approach.

- *"I've noticed a lot of services leaning towards preventative measures instead of harm reduction, and I think [prevention] is rooted in judgment and [is] instructional versus harm reduction, [which] allows people to be transparent, their full selves, and room for real implementation of support."*

- *"I feel like [with] the anonymous programs, they're too anonymous because if people don't recognize that other people have issues, or when people go to those meetings and they don't see themselves in somebody else, then it's hard for people to understand that they have an issue. […] when everything's so secret, it blocks people from getting proper help."*

Latino/a/Latinx/Latine: Participants shared that some support currently available includes: Alcoholics Anonymous (Triple A); church or faith-based and spiritual guidance; free walk-in clinic and community health clinic; and inpatient and outpatient treatment programs. While these services exist, participants noted that greater awareness and visibility of these resources are needed. They suggested several ways to better support the community. Storytelling from community members who have been personally affected by alcohol use or FASD was recommended as a way to raise awareness. They said that harm reduction approaches, meeting people where they are, rather than using judgment or fear-based messaging, is the best strategy for education.

- *"Education, education, and education and should start as early as the elementary school level. Children should be taught about the consequences of alcohol use, including the health risks such as liver damage and the long-term impacts."*
- *"Sharing statistics about alcohol use and its consequences could help increase awareness and reduce stigma. Seeing the data might make the data seem more real."*

Somali: The participants discussed that in the past 10 years, opinions and beliefs have started to change when discussing disabilities in general. They expressed the importance of bringing religious leaders into the conversation to help engage families. They believed that the families would listen to community religious leaders. The participants also noted that there are community members who are offering to talk through the problems families may be facing.

- *"...When religious people talk about [how to] come [together] as a community..they [religious institutions] have resources that they can refer to families because parents do listen to these religious people because they do listen to their lecture[s]."*
- *"Now, we see that many centers have been opened, like places that support children with autism and similar conditions. I think we've all*

seen that. We believe in to read Qur'an over them [children], instead of taking them to professional places for help."

- *"Yes, there are people in the community you can talk to. You can take the issue to those who work within the community. The mothers come together—they help each other. Everyone is going through something. The mothers are struggling, searching for their children. They love them and want them to come back and be respectful again. They seek help in the community, and they get support."*

Community Information on Children's Health

Finally, ACET asked how and where the community discovers and receives information about children's health. Where participants get information about children's health varies across the focus groups. **Most cited social media and family over health professionals** as the most trusted sources of information on children's health. Some participants noted a **lack of culturally appropriate materials** and information in languages other than English. From the Latino/a/Latinx/Latine group, they noted that while some information is in Spanish, the stigma attached to alcohol consumption while pregnant would prevent individuals from picking up brochures and flyers; they encourage using QR codes instead. Somali and Black/African American participants encouraged having individuals **who look like them and who understand cultural cues and contexts** to be able to have this challenging conversation with birthing persons and families. There was general agreement that **more education and public awareness campaigns** are needed to shift social norms around alcohol use and pregnancy. Education and public awareness campaigns need to be a **"boots on the ground"** effort. The community needs to see individuals doing this education in the places that they socialize, work, play, and pray.

1. ***Where do you typically go to find information about children's health and development?***
    a. **Are there community events where information is currently shared?**
    b. **Think about where you get your information. Which social media platforms might be most effective for getting information?**

Black/African-American: The participants discussed using social media, family, and other resources to get information about children's health and development. They couldn't think of specific community events; they did explain that whatever community events exist that they need to be tailored to the community in which they occur. Also, the work needs to be in person and in community with the people who need education about PAE and FASD. The participants also pointed out that birthing parents may not go to prenatal appointments, but those who are using WIC and SNAP will go to those meetings, so that is an opportunity to get the information in front of those individuals.

- *"...It has to be culturally specific because there's a distrust with white people in the Black community of taking our kids. Like, I'm not going to tell you because you're going to take my child."*
- *"When I was breastfeeding with the twins, there is a Black Moms Breastfeed or something like that on social media that I joined so that I could talk to other moms who were doing it too."*
- *"TikTok is where you need to be."*
- *"...You also got to do some boots on the ground type work... start taking it up the ladder to address it at a higher level, some of the real work that's going to get these things taken away, it's just a band-aid over a broken leg at that point, though still needed. It's still a needed band-aid, but I think it's a both-and situation of really trying to actually look into that. Who's going to sue these alcohol companies, and who's going to really get this out of these places that are really overly impacted by drugs and alcohol?"*

Latino/a/Latinx/Latine: Participants believed that social media platforms like TikTok were the place people got most of their information. However, participants noted that the quality of information often depends on the algorithm, and it's important to compare multiple opinions. Online resources, like ChatGPT, Google, and internet searches, were also sources of information that participants pointed to as popular

within the community. One participant mentioned that she also gets information about the health of her daughter from their healthcare provider during clinic visits.

Somali: Participants discussed that conversational and written language needs to be more sensitive, that Somali basic dialect is best and English second, on documents or in conversation with families and birthing persons. They also pointed out that it's good to have community representation, someone who can relate to you and understand the cultural norms and stigmas, so they can be patient and understanding. The participants noted places that many in the community get their education on health, may be through county programs and WIC clinics.

Final Thoughts

1. ***Before we wrap up the focus group, is there anything else you would like to share with us?***

ACET also asked if there were additional things that the participants thought were important to the conversation about PAE & FASD specifically, or anything they felt was left out of the questions that they wanted noted.

Black/African American participants discussed that due to their socioeconomic status and education level that their experiences are possibly unique to them and the way they relate to the topic. They also were insistent that harm reduction was the way to work through many of the issues that surround alcohol and substance use.

- *"I think where we get our resources from should be taken with a bit of a grain of salt because none of us are necessarily the population that's seeking—that is in need of the support, right? …I think of a young lady in ATS right now who has a baby, and where she might be getting her support or one of our kids on extended foster care, where she might be getting her support. I think that the answer might be significantly different for them, at least I hope."*

Latino/a/Latinx/Latine participants emphasized the need to address common misconceptions about alcohol use, including the belief that "just a little" doesn't

cause harm. One participant noted that people may avoid taking material in public areas because they don't want others to see them, so discreet options are important.

- *"Education starts with elementary school and having that heart and liver and showing it; alcohol, drugs, vaping, this is what it looks like from an early age, to the parents too. It starts with one. Fairs at school; to grab parents to come to the school for activities. Festivals make it fun."*

Somali participants pointed out that families are in need, and their responses reflect a community issue larger than the topic of PAE and FASD. And they hope that starting these conversations and eliminating the stigma and bias can help families and children.

- *"The truth is, these children are suffering—and everyone seeing it…They need help support, and the Somali community must come together, join hands, and stand in unity. Many of these children are hanging out on the streets and using social media. They're dying every day, and no one knows how or why. Something must be done. Safety spaces need to be created, and also need they need to be brought in from the streets. They need shelters and, most of all, good care. These children need a lot of help."*

Recommendations

The insights gathered from focus group participants underscore the importance of culturally responsive, community-centered approaches to FASD education. Participants shared a range of perspectives, highlighting both the barriers to engagement, such as stigma, mistrust, and lack of accessible information, and the opportunities to build meaningful connections through trusted relationships and tailored outreach. Based on these community voices, the following recommendations aim to guide future efforts by Proof Alliance and its partners:

- **Building trust** within the communities will be the most important aspect of partnerships between Proof Alliance and the Community Partners. Due to the sensitive and often stigmatizing nature of alcohol and pregnancy and the complications that can arise, diverse communities may be unwilling or uninterested in engaging in those conversations with individuals who are not a trusted person in the community. It might be important to build trust through small engagements with trusted community partners and (in some cases) religious leaders, attending community-based events, and inviting community members to educational opportunities where they can listen and learn without a requirement to be vulnerable.

- **Increase public education** efforts about FASD through social media sources like TikTok, early education in schools (parents or caregivers will listen to the little kids and education in high school would help for young people who are nearing sexual engagement), and inviting community leaders and organizations; such as ministers/pastors to the conversation would be important to the community.

- **Key culturally responsive messages for Proof Alliance's web and print materials** emerged from broader conversations with community members. These messages should **prioritize empowerment of individual choice** by providing **accessible, nonjudgmental information** about Fetal Alcohol Spectrum Disorders (FASD) related to the following community-specific themes**.** Proof Alliance should collaborate with

community partners to test these statements and ensure they reflect and respond to the needs and perspectives of the broader community:

- **Black/African American**
  - Message (Focused Points to Share): In general, the participants believe that alcohol use is normalized (e.g., family functions, social situations) within the Black/African American community. They also felt that alcohol use while pregnant is common amongst younger birthing persons (20s and 30s) than older birthing persons (30s and older). They also believe that alcohol use while pregnant is often connected to addiction. Messages should be emphasized with a harm reduction approach and care for the birthing person and their families.
  - Language that resonates would be "harm reduction"-centered as opposed to language that describes a stereotypical approach of those who use/abuse alcohol, as being too far gone for any help or assistance.
    - **"Caring for You Means Caring for Baby—One Step at a Time."**
      There's no shame in asking for support. If you're drinking and pregnant—or thinking about getting pregnant—there are people who understand and want to walk with you, not judge you. Let's talk options, not blame.
    - **"In Our Community, We Look Out for Each Other."**
      Alcohol can be a part of life's celebrations—but when you're pregnant, even a little can affect your baby's health. You're not alone—resources and real support are here to help you reduce harm in ways that make sense for your life.
    - **"Support Over Stigma—Because Every Story Matters."**
      Pregnancy can be complicated. If alcohol is part of

your journey, there are harm reduction tools that respect your experience and protect your baby. We believe in care, not judgment.

- **"Real Talk. Real Help. Real People Who Get It."** Whether it's stress, addiction, or just life happening—if alcohol is involved during pregnancy, you deserve support that's rooted in understanding, not stereotypes. Let's build health with compassion in mind.

- Additional Considerations about Community Partners as Messengers: Individuals seeking to engage meaningfully with this community should reflect its demographics, so that peer conversations and within-group dialogue are authentic and trusted from an experiential standpoint as a person within the community. Messages from persons outside of the community need to be accompanied by a deep understanding of the Black/African American experience (i.e., consequences of seeking help may be perceived as barriers). And so partnering with trusted community organizations—such as REBOUND—that are respected for their ability to connect with and represent the community's diverse perspectives is of high value.

- **Latino/a/Latinx/Latine:**
  - Message (Focused Points to Share): Promote a deeper understanding that any amount of alcohol, while perceived by participants to be socially acceptable in some instances (e.g., religious settings, coming of age experiences within familiar settings), may cause harm. While social attitudes reinforce the idea that small amounts of alcohol are irrelevant to fetal development, social pressures may lead to continued use during pregnancy
  - Language that resonates would exclude words like "addiction" or "alcoholic", because of their stigmatizing

nature, which discourages participants from seeking support when needed. Ensure educational materials are always available in both English and Spanish.

- **"Even a little alcohol during pregnancy can affect a baby for life."**
  It may seem harmless in small amounts, but no known amount of alcohol is safe during pregnancy. The more we know, the better we can care for ourselves and our families.
- **"Our traditions matter—and so does protecting future generations."**
  Alcohol may be part of celebrations, but during pregnancy, even one drink can carry risks. Learning the facts helps us make choices rooted in love and care.
- **"When young people learn, families grow stronger."**
  Early education about alcohol and pregnancy can inspire conversations at home. When we teach the next generation, we open the door for parents and elders to learn too.
- **"Support without shame. Respect without labels."**
  If you're pregnant and have questions about alcohol, there are people who will listen and support you—without judgment, without labels, and with real care.

- Additional Considerations about Community Partners as Messengers: Proof Alliance should consider partnering with trusted community organizations, such as HACER, that engage with the diverse Latino/a/Latinx/Latine community. Participants believed that educating younger people (perhaps as early as middle school) can influence older community members to pay attention to information about PAE/FASD. They emphasized that introducing this

education in school settings could also engage parents and encourage them to learn more.

- **Somali**
  - Message (Focused Points to Share): Proof alliance should consider partnering with religious leaders within the Somali community. Focus group participants believed this is the main way to get any education about PAE/FASD out to the community. While they had a difficult time discussing alcohol, as it is prohibited within the Islamic community, they do believe that religious leaders could help bridge that conversation.
  - Language that resonates would be knowing the prohibitions in the Islamic community, so avoiding initial language like alcohol, addiction, and instead using, when possible, neutral language. In the scope of our work with this community, it was difficult to articulate what might be considered neutral language (e.g., not producing stigma, or in direct contrast to the religious prohibition), and perhaps further discussion with religious leaders could illuminate what this language could be.
    - **"Protecting our youth begins with honest conversations."**
      Our community values health, family, and faith. With trusted guidance, we can talk about how to protect the next generation from harmful influences in the wider society.
    - **"Healthy families start with informed choices."**
      Faith and knowledge go hand in hand. Trusted community leaders can help guide conversations that protect mothers, children, and our future.
    - **"Strong communities care for every generation."**
      In a world full of outside pressures, our strength is in how we care for one another. Supporting youth and families with compassion keeps our values strong.

        - **“Community health is a shared responsibility.”** With leadership from our elders, faith leaders, and health advocates, we can protect our families and support well-being—while honoring our beliefs.
    - Additional Considerations about Community Partners as Messengers: Partnering with trusted community organizations and leaders—such as Bureeqo Dhair and emerging groups like Alliance Wellness—is essential. It’s important to note, initial conversations with the community may center on youth exposure to alcohol within broader social contexts and how families approach prevention and care, rather than focusing solely on birthing persons.
- ACET found that while communities may differ culturally, their communication needs are remarkably aligned—they value respectful engagement, culturally aware messaging, and attention to language differences that improve understanding. **Participants did not identify a specific messaging style** but emphasized the importance of Proof Alliance **being present (i.e., visible and available) in the community** and actively engaging with individuals **to build trust and gain clarity** around needs and concerns. Most importantly, building genuine relationships within communities will be essential in shaping future dialogue.
- Participants emphasized that **effective messaging** should be **compassionate and stigma-free,** recognizing the **complex realities individuals face.** It should reflect **core community values and support re-engagement by Proof Alliance through**:
    - Family **(all communities),**
    - Spirituality (Engaging of supportive religious leaders **- Somali Community Specific),**
    - Mutual care **(i.e., individual community members partnering together by caring for and sharing resources),** and
    - **Use clear, inclusive language** that is available **in multiple languages.**

- Centering collective well-being, the materials should emphasize shared responsibility in supporting healthy pregnancies and strong families. Above all, messages must **foster trust** by highlighting **collaboration with community partners** and **honoring individual autonomy, encouraging informed and respectful decision-making.**
    - Develop and distribute **culturally relevant, sensitive, responsive, and accessible materials** tailored to different audiences.
        - E.g., develop materials in Somali (basic language) and Spanish.
    - **Bilingual outreach** is equally important.
    - QR Codes, which are discreet and easy to carry on a phone vs. brochures or flyers.
    - **"Boots on the ground"** conversations within the community by **co-creating messaging for web and print with Community Partners.**
        - E.g., utilizing the community partner list included in the report.
    - Center education on **similarities and differences** between FASD and other mental and behavioral issues that may present within individuals who live with FASD, and an acknowledgment and build awareness that individuals living with FASD have their own unique lived experience and needs.
- It is essential that **individuals leading FASD education efforts reflect the communities they serve, both in identity and lived experience.** Educators should not only look like the community but also understand its cultural context, norms, and the unique stigmas surrounding alcohol use and pregnancy. This cultural alignment helps foster trust, relevance, and openness in conversations that are often sensitive and deeply personal.

The findings from the focus groups make it clear that effective FASD education must be rooted in culturally responsive, trust-based approaches that reflect the lived realities of diverse communities. To create meaningful change, Proof Alliance and its partners must **prioritize relationship-building, invest in trusted messengers, and**

design outreach efforts that honor cultural norms and reduce stigma. From leveraging social media and early education to creating linguistically and culturally tailored materials, successful strategies will center the voices and needs of the communities most impacted. When educators reflect the identities and experiences of the people they serve, and when learning environments are welcoming and respectful, conversations around FASD become not only possible but powerful. These community-driven insights provide a strong foundation for shaping educational initiatives that are inclusive, respectful, and ultimately more effective in promoting children's health and well-being.

Appendix

- Focus Group script
- Community Partner List

PA CR FASD P. Focus Group Script

Introduction

Facilitator: Welcome, everyone, and thank you for joining us today. My name is [INSERT NAME], and I will facilitate this session. [NOTE: Co-facilitator introduction as needed]. We work for ACET, Inc., which specializes in research and community engagement. We are collaborating with Proof Alliance to conduct this focus group. Proof Alliance is a non-profit organization dedicated to preventing Prenatal Alcohol Exposure (PAE) and supporting all impacted by Fetal Alcohol Spectrum Disorders (FASD). Proof Alliance raises awareness about the risks of alcohol use during pregnancy and provides resources to those impacted by FASD. Today's focus group aims to understand community perspectives on alcohol use during pregnancy. The information gathered will inform the development of effective and culturally relevant prevention strategies and support systems for FASD.

[NOTE for facilitator: Point out any logistics participants might need, such as restrooms, water, snacks (*ensure these are culturally appropriate)*, etc.] Does anyone have any questions about the space or where anything is?

Facilitator: Before we begin, I'd like to cover a few important details:

1. This focus group will last no longer than 90 minutes.
2. Today's conversation will be recorded with your consent. When you checked in, you received two copies of the consent form—one to sign and return, and one to keep for your reference.
3. I want to highlight two key points from the consent form:
    1. There are no right or wrong answers; we are interested in your honest opinions. Please feel comfortable sharing them.
    2. Your participation is voluntary. You may decline to answer a question, step out, or leave at any time, and this will not affect your eligibility to receive your gift card incentive.

Facilitator: Does anyone have any questions before we begin?

Facilitator: To get us started, let's do a quick icebreaker: Please share your first name and your favorite way to relax. I'll go first.

Facilitator: Thank you for sharing. It's interesting to hear everyone's different perspectives. Now, let's move into our discussion. My first question for the group is:

Focus Group Questions

Awareness

1. Before today, had you heard of Proof Alliance?
    - If yes: Have you heard about the work Proof Alliance does? If so, where did you first learn about it? How did you feel about it when you first heard?
2. Before today, had you heard of Prenatal Alcohol Exposure (PAE) or Fetal Alcohol Spectrum Disorders (FASD)?
    - If no: Thinking about alcohol use in your community, which thoughts or images come to mind first?
    - Hearing the phrase 'a child affected by alcohol before birth' brings up which thoughts or associations for you?

Facilitator: Thank you for sharing your thoughts on that. To ensure we're all on the same page as we move forward, I'd like to take a moment to review some key definitions that will be helpful for our discussion today

Key Definitions (*Add to chat for virtual)*

- **Prenatal Alcohol Exposure (PAE):** This refers to when a developing baby is exposed to alcohol during pregnancy due to the pregnant person's alcohol consumption.
- **Fetal Alcohol Spectrum Disorders (FASD):** FASD is a spectrum of conditions that result from prenatal alcohol exposure. FASD can result in a range of physical, behavioral, and intellectual disabilities, varying from mild to severe.

Facilitator: Thank you for reviewing those definitions. Keeping those in mind, I'd like to now ask some questions about community perspectives and how Proof Alliance's initiatives can be most helpful with your community or the community that you serve.

Perspectives

1. How common do you perceive alcohol use to be within your community?
2. Are there cultural, spiritual, or religious values that have influenced your views about alcohol use?
3. Have you or someone you know been affected by FASD? If so, what kind of challenges did you/they experience?
4. How have families in your community supported children with FASD?
5. What kinds of supports or services have you seen in your community for people who struggle with alcohol use?
    - Prompt:
        i. Detail the types of resources that would be most helpful for your community.
        ii. This could include things like brochures, a website with information, or connections to local support services.

Community Informational Resources

1. Where do you typically go to find information about children's health and development?
    - Prompts:
        1. Are there community events where information is currently shared?
        2. Think about where you get your information. Which social media platforms might be most effective for getting information?

Closing

Facilitator: Before we wrap up the focus group, is there anything else you would like to share with us? Any final thoughts or comments are welcome.

Facilitator: Thank you all so much for your time, your thoughtful contributions, and your willingness to share your perspectives with us today. Your input is incredibly valuable to Proof Alliance as they work to develop effective strategies to support the community. For more information about Proof Alliance and their work, please visit their website at proofalliance.org. In addition to Proof Alliance's website, they've also provided a compilation of other FASD resources that you may find helpful. We will be sure to provide that information to you. We appreciate your participation!

Proof Alliance Community Partner Contact Information

Partner Organization	Point of Contact	Email Address	Phone Number	Agreed to Be on List
Rebound, Inc.	Carmeann Foster, JD, LICSW, Executive Director	cfoster@reboundmpls.org	612-558-6259	Yes
Hispanic Advocacy and Community Empowerment through Research (HACER)	Rodolfo Gutierrez, Executive Director	rodolfo@hacer-mn.org	651-401-0011	Yes
Center for Inclusive Childcare (CICC)	Bureeqo Dahir, RPBD Specialist	bureeqodahir23@gmail.com	651-603-6265	Yes
Washburn Center for Children (WCC)	Julie Carver, Director, Marketing and Communications	julie.carver@washburn.org	612-767-3721	Yes
Hmong Breastfeeding Coalition (HBC)	Lia Yang	lia.yang@co.ramsey.mn.us	651-279-2985	Yes
Better Endings, New Beginnings (BENB)	Jodee Kulp, Executive Director	jodeekulp@gmail.com	612-408-2942	Yes