TITLE V MATERNAL & CHILD HEALTH NEEDS ASSESSMENT

COMMUNITY PERSPECTIVES · ARIZONA · DECEMBER 2020

NEEDS ASSESSMENT TEAM:

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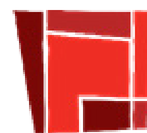
IN COLLABORATION WITH



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We would like to thank the many people who have helped us carry out the community perspectives component of the Title V Maternal and Child Health Needs Assessment. We are greatly indebted to Arizona Department of Health Services; the Title V Maternal and Child Health Needs Assessment Steering Committee; and other partners who contributed to the design and organization of our data collection activities. You have enabled us to engage with so many communities across the state of Arizona. Many thanks also to all those who participated in the data collection activities. We value your time and your insights. We have tried to give voice to your views in the following pages. Any omissions or errors are entirely our responsibility.

The University of Arizona Needs Assessment Team

1 BACKGROUND

In this report we present findings from studies conducted as part of the Arizona Title V Maternal and Child Health Needs Assessment for 2020-2025. Title V is a federal program that focuses on improving the health of all mothers and children. In 1981 a Title V block grant was created to serve three populations: pregnant women and infants, children, and children with special health care needs (CSHCN). Every five years, state Title V MCH agencies are required to conduct comprehensive needs assessments to identify state maternal and child health needs and prioritize them for Title V block grant funding. The state agency responsible for Title V in Arizona is the Arizona Department of Health Services (ADHS). ADHS designed a comprehensive needs assessment including several components. These included: an analysis of trend data on Maternal and Child Health Indicators in Arizona; an Online Public Survey; an Assessment of the Capacity of Arizona Department of Health Services to implement Title V; Focus Groups with under-served communities; a Tribal Needs Assessment; Community Forums; and a Priority Setting exercise done by ADHS. A Steering Committee was set up to guide and oversee the process. University of Arizona was contracted to carry out the focus groups and community forums components in collaboration with ADHS and the Steering Committee. The final needs assessment report integrated findings from all components. Thus, what is presented here only represents one part of the overall Title V Maternal and Child Health Needs Assessment.

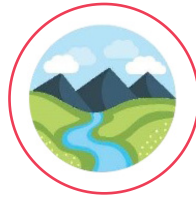
2 PURPOSE

The purpose of the focus groups and community forums was to provide spaces for families and youth from under-served communities to talk about their health needs and their experiences of using health services. Communities were invited to participate in these events to help identify needed services, for the state of Arizona, including:

- Preventive and primary care services for pregnant women, mothers and infants up to age one.
- Preventive and primary care services for children.
- Services for children with special health care needs (age 0 - 26).
- Services for youth (age 10 - 26).

3 METHODS

Three approaches were used:



(i)
River of Life planning tool was used at statewide meetings to identify issues in maternal, child and adolescent health for the state of Arizona.

(ii)
Focus groups and individual interviews were used to explore issues relevant to specific communities prioritized for this study.

(iii)
Community forums were used to help prioritize issues for different counties throughout the state.

Building on the work of state and county health departments and partners, and under the guidance of the Steering Committee, we targeted under-represented and under-served groups. The Steering Committee compiled a list of high priority communities that should be consulted, including both health service providers and community members/service users. This list was used to conceptualize our approach to reaching the priority communities, bearing in mind that some individuals belong to overlapping categories (see Figure 1).

With the help of members of the Steering Committee and many other partners, we reached representatives from each of these communities. We were able to cover every county in the state, including rural, frontier, border and urban locations (see Figure 7). A team of 5 faculty and 11 students from the University of Arizona's Mel and Enid Zuckerman College of Public Health worked on the assessment from June 2019 – August 2020.

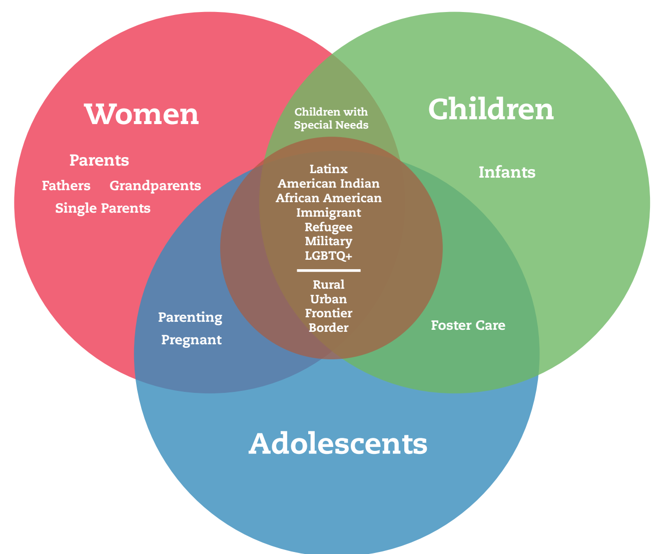


Figure 1: Priority Communities identified for Participation

3.1 River of Life Tool used at Statewide Meetings on Health

3.1.1 Goals:

1. To gather information about maternal, child and adolescent health needs for the whole state
2. To build contacts to help us conduct the focus groups

3.1.2 Participants

From June to August 2019, members of the team attended four meetings at different locations across the state (see Table 1). These meetings were attended mainly by health care workers and people working for community organizations. There were a few community members. At each meeting, we invited attendees to a special session for the Title V Needs Assessment data collection. The number of participants in the sessions ranged from 20 – 70.

	Name and Location of Conference	Attendants	No. participants in Title V study
1	Adolescent Health Conference, Phoenix	Youth and youth serving organizations	21
2	Arizona Community Health Outreach Worker (AZCHOW), Tucson	Community health workers, community organizations	72 (estimated)
3	Arizona Rural Women's Health Network Symposium, Sedona	Health care workers, community organizations, community members	69
4	Arizona Rural Health Conference, Flagstaff	Health care workers, community organizations, community members	12

Table 1: Statewide Meetings

3.1.3 Procedure

We used the **River of Life** method to collect information.

River of Life is an interactive planning tool designed for use with groups of people from different backgrounds. For example, members of the group may speak different languages or have different levels of education. Because the tool is visual, everyone can contribute and understand. We used the River of Life tool to set goals and identify assets and barriers to achieving these goals, for maternal, child and adolescent health planning.

The following steps were used:

1. Participants were divided into groups of 5-10.
2. Each group was provided with a large sheet of paper and different colored pens.
3. The MEZCOPH team provided a brief slide presentation to provide instructions and facilitate the River of Life activity.
4. Each group was asked to identify one important goal for maternal, child and adolescent health in the communities where they lived and worked.
5. Next, they were asked to discuss resources in the community that would help achieve this goal
6. Then they were asked to think of barriers that would make it hard to reach the goal.
7. Each group was asked to draw the results of their discussion on the sheet of paper in the form of a river. The goal was to be drawn at the head of the river, the resources and barriers along the river. Groups could use any colors, symbols or pictures to describe what they thought.

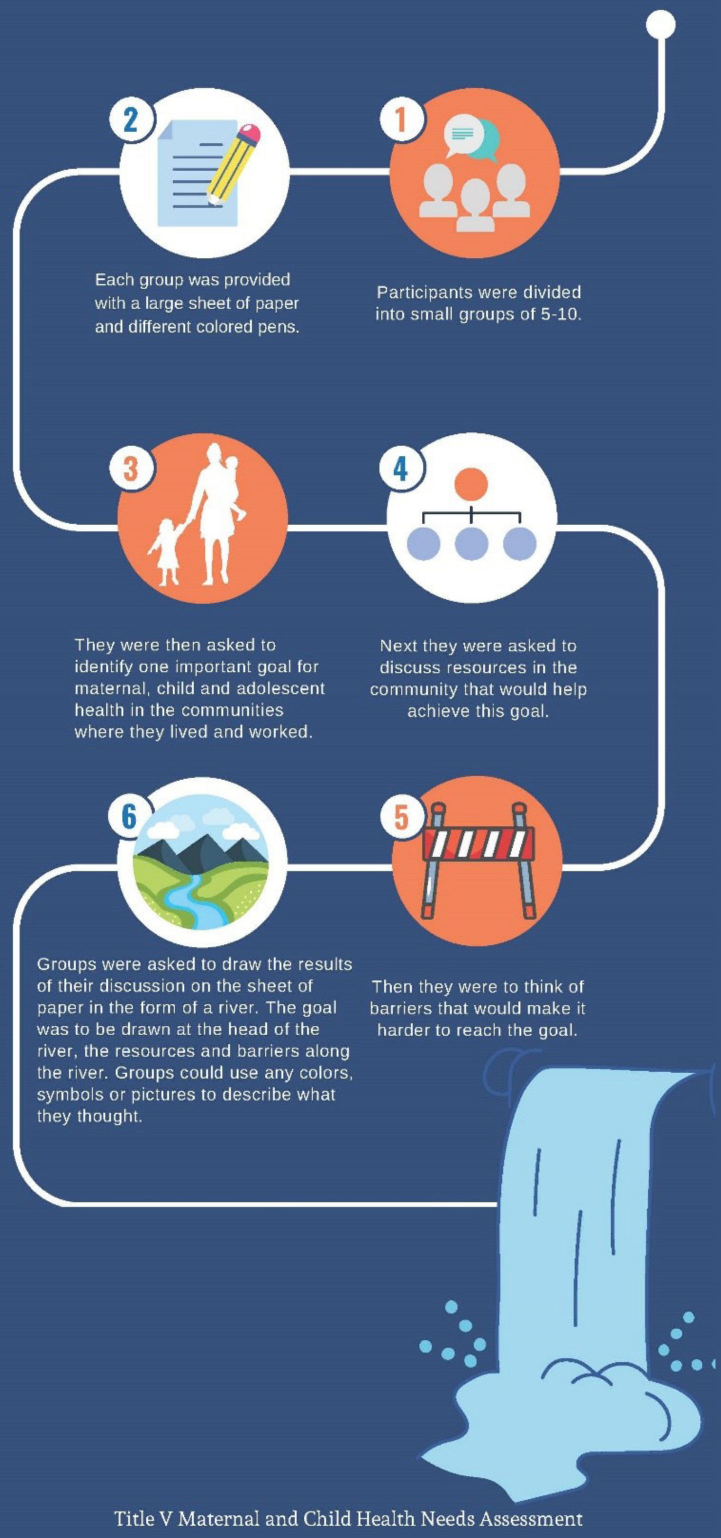


Figure 2: River of Life Activity
1
Participants were divided into small groups of 5-10.
2
Each group was provided with a large sheet of paper and different colored pens.
3
They were then asked to identify one important goal for maternal, child and adolescent health in the communities where they lived and worked.
4
Next they were asked to discuss resources in the community that would help achieve this goal.
5
Then they were to think of barriers that would make it harder to reach the goal.
6
Groups were asked to draw the results of their discussion on the sheet of paper in the form of a river. The goal was to be drawn at the head of the river, the resources and barriers along the river. Groups could use any colors, symbols or pictures to describe what they thought.
Title V Maternal and Child Health Needs Assessment

3.1.4 Analysis

We collected 32 River of Life drawings. A Framework Analysis was used to analyze the data. We created a table with topics on the left-hand column and the river of life drawings along the top row. In each box we entered notes written on each river of life drawing about that topic. For a summary of findings, see Appendix 1.

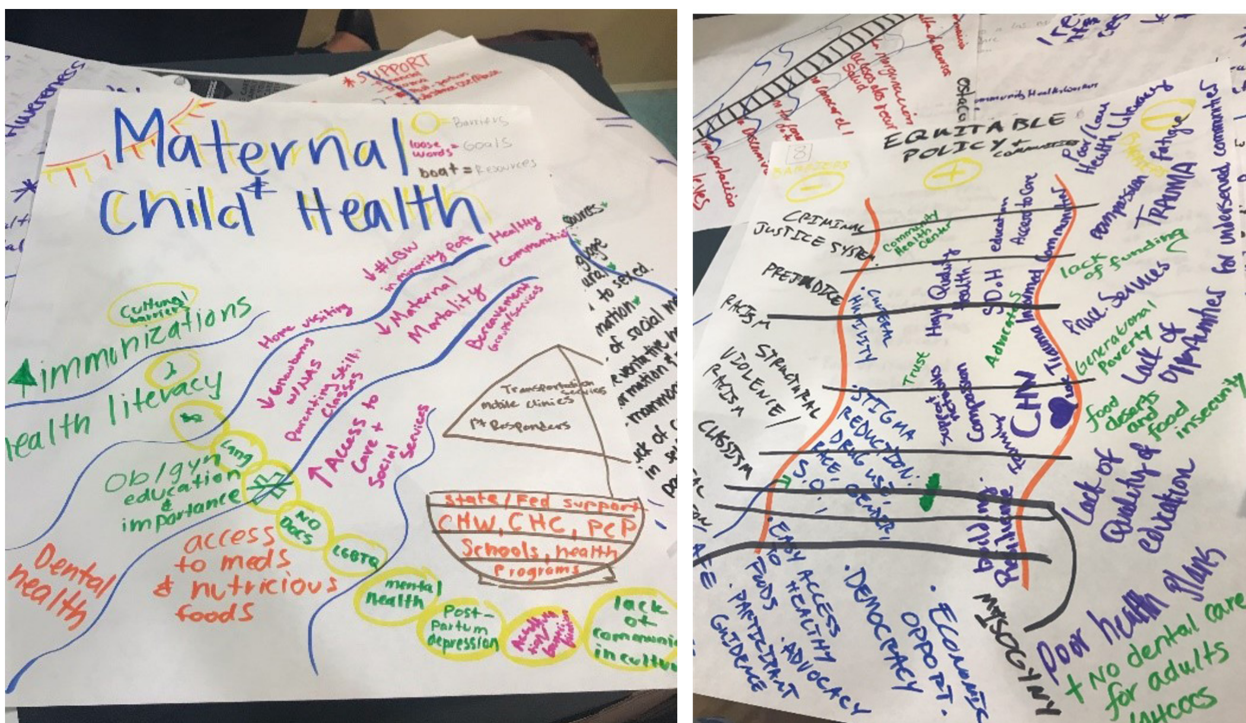


Figure 3: River of Life Activity: Example Drawings

3.2 Focus Groups and Individual Interviews

3.2.1 Goals

1. To collect more in-depth information about maternal, child and adolescent health needs across the state;
2. To identify specific needs of underserved communities in Arizona.

3.2.2 Participants

The communities were identified in consultation with Arizona Department of Health Services and the Steering Committee. The focus was on those not traditionally heard who are under-represented in research and services. Participants for the focus groups were chosen based on two criteria:

1. Resident of Arizona
2. Belongs to the community of interest or works for an organization that serves this community.

We conducted 17 focus groups with adults and 8 with youth, giving a total of 25. Each focus group included between 4-12 participants. In addition, 14 individual interviews were conducted. Six were with service providers and eight were with individuals from communities of interest who were unable or unwilling to attend focus groups. With the help of many partners, we reached 135 individuals from several hard to reach communities (see Table 2). The number of focus groups and interviews was limited by time and financial resources.

	Community	Partners	Location	No. focus groups	No. interviews
1	Refugees	International Rescue Committee (IRC); Women's Health Clinic Student	Tucson Phoenix Phoenix		1 1 3
2	African American	Coalition for African American Health and Wellness; South Phoenix Health Start	Tucson Phoenix	1 1	
3	Latino	Hope Network SEAHEC, Winchester Heights Mariposa Community Health Clinic	Phoenix Wilcox Nogales	3 2 1	
6	Rural	WIC	Pinal County		1
7	Families with children with special health care needs	Raising Special Kids	Phoenix, Yuma	3	
8	LGBTQ+	Arizona Trans Youth and Parent Organization (AZTYPO)	Phoenix	1	3
9	Foster Families	Onward Hope	Phoenix		2
10	Service Providers	First Things First	Phoenix	3	1
	TOTAL			**17**	**12**

Table 2a: Adult Focus Groups and Individual Interviews

	Community	Partners	Location	No. focus groups	No. interviews
1	High School Students	Eastern Area Health Education Center (EAHEC)	Cochise, Graham, Pinal Counties	5	
2	Youth involved in the justice system	Eastern Area Health Education Center (EAHEC)	Graham County	1	
3	Youth	Mariposa Community Health Center	Nogales	1	
4	Young pregnant and parenting mothers experiencing homelessness	Our Family Services	Tucson	1	
5	Youth Service Providers	OneNTen, Job Corps	Telephone Tucson		1 1
	TOTAL			**8**	**2**

Table 2b: Youth Focus Groups and Interviews

3.2.3 Organization

To help organize the focus groups we used:

1. contacts collected from the statewide meetings
2. contacts suggested by the Steering Committee
3. our own ties to partner organizations

Phone calls, emails, and in-person meetings were held to discuss the criteria for focus group participation; selection of a location and time convenient for participants; and appropriate incentives. Arranging the focus groups took several months. Gaining entry into community organizations and schools was the biggest hurdle due to issues of trust and busy schedules. We gave communities a flier in English and Spanish and contact information. Each participant received a $20 cash incentive for completing a focus group or individual interview.

3.2.4 Procedure for Focus Groups

The focus groups were conducted from August – November 2019. They lasted from 1-2 hours and most took place at lunchtime or in the early evening, as this was more convenient for participants. Each focus group had a facilitator and note-taker. They ranged in size from four to 12 participants. Seventeen focus groups were in English and six were in Spanish. Most were audio-recorded with permission from all participants. Notes were taken by hand or on a laptop by the note-taker.

Participants were greeted on arrival and invited to sit around a single table. Each was given a consent form and a 13-question demographic survey form to fill in while waiting for others to arrive (results of the demographic surveys are presented in Appendices 5a and 5b). Focus groups began with introductions by the facilitators, then the participants. The facilitator then explained the purpose of the meeting. A short questionnaire, with open ended questions, was used to guide the discussion (see Appendix 4a). Questions were asked about maternal, child and adolescents health issues in the community, access to health information and services, positive and negative experiences with health services, and suggestions for improving the health of mothers, children, and adolescents. At the end of the discussion participants were thanked and provided with a $20 gift card. Food was provided, such as tacos or sandwiches or snacks such as clementine's, bananas and apples. We provided childcare on-site, in the presence of the children's guardians.

After participants had left, the facilitator and note-taker held a debriefing. The purpose was to review how the focus group went, suggest improvements for next time, discuss key points that came up, and ensure all the information was captured in the notes.

3.2.5 Procedure for Individual Interviews

Fourteen Individual interviews were conducted, six with service providers and eight with people from communities of interest who could not attend a focus group. Eleven were in person and 3 were via telephone. Each lasted about one hour. Different sets of questions were used depending on whether the person interviewed was a service provider or a community member. For service providers questions were asked about the services provided to the community of interest (for example, refugees or youth). See Appendix 4b for these questions. For community members, including refugees, LGBTQ+ and foster parents, the same questions were used as for the focus groups (Appendix 4a).

3.2.6 Ethical Approval

The study was approved by the University of Arizona's Institutional Review Board (IRB). All participants received detailed information about the study and its objectives, and participation was voluntary. All participants completed written informed consent forms prior to the data collection. Additionally, parental consent was obtained for all interviews conducted with youth. Participating youth received information about the study and also completed their own informed consent/assent form.

3.2.7 Analysis

A team of one faculty and three students analyzed the focus group and individual interview data. The data consisted of audio recordings and notes taken by the note-taker. All personal identifiers were removed from the data prior to analysis. Recordings were used as a back-up if information was missing from the notes or if they were unclear. The final version of notes from each focus group or interview was then imported into a computer program designed for analyzing textual data, MAXQDA. First, the key topics that were discussed in each focus group were identified. These topics were converted into a codebook in MAXQDA. Each set of notes was then coded using the codebook. Coding involved highlighting and tagging each piece of text that addressed the topic of a code. To make sure that all members of the analysis team coded text in the same way, each transcript was coded by one team member, then reviewed by another team member. The entire team reviewed the coding process together during weekly meetings over several months. Where team members made different coding choices, these were discussed until everyone was in agreement. Once all notes had been coded, the faculty member reviewed all of the coding again to ensure consistency. For the report writing, a report outline was developed with headings and sub-headings. Segments of coded text were retrieved for each sub-heading and were reviewed to identify common points and representative quotations that were then included in the text of the report. Summary Tables of results are in Appendix 2.

3.3 Community Forums

3.3.1 Goals

1. To obtain feedback on the data that had previously been collected.
2. To prioritize needs for specific counties.

3.3.2 Participants

County selection and location for the community forum was done by ADHS. The aim was to ensure people from most counties in the state could attend at least one forum. There were 6 community forums held in person and the remaining 3 were held virtually due to the covid-19 pandemic.

Location	Date	Organization	Number of Participants
Kingman (Mohave)	2/27/2020	In-person	5
Flagstaff (Coconino)	2/28/2020	In-person	17
Sierra Vista (Cochise)	3/9/2020	In-person	14
Eloy (Pinal)	3/10/2020	In-person	13
Tucson (Pima)	3/11/2020	In-person	25
Eagar (Apache)	3/12/2020	In-person	9
Yuma	7/7/2020	Virtual	10
Statewide (Spanish)	7/8/2020	Virtual	2
Maricopa	7/9/2020	Virtual	21

Table 3: Community Forums

3.3.3 Procedure

Community forums began with introductions from the Head of the Bureau of Women's and Children's Health and the Facilitator, followed by presentations from Arizona Department of Health Services (ADHS) and the University of Arizona team. ADHS presented results of quantitative analysis of maternal and child health secondary data sources. University of Arizona presented results from the River of Life activity from the Statewide Meetings, and from the Focus Groups and Individual Interviews. Both presentations used Power Point slides.

There were two stages of data collection during the community forums:

(i) feedback from participants on results that were presented and

(ii) an exercise to prioritize maternal and child health issues in the locality

Feedback

Participants were invited to ask questions and provide feedback on the presentations of results given by the ADHS and University of Arizona teams. Participants were asked:

– was there anything surprising?

– was there anything that confirmed what you already knew?

Prioritization exercise

The prioritization exercise consisted of three stages:

1. Participants were divided into small groups and each group was asked to identify 5-7 individual issues of concern to MCH populations in their communities.
2. The facilitation team grouped the individual issues that had been identified into categories.
3. The facilitator invited participants to guide him in placing the categories on a two-by-two prioritization grid on a large board visible to all.

The four sections of the grid were labelled along two dimensions: higher/lower need, and easier/harder to change as follows:

Lower Need/Easier to Change	Higher Need/Easier to Change
Lower need/Harder to Change	Higher Need/Harder to Change

Table 4: Community Forum Prioritization Grid

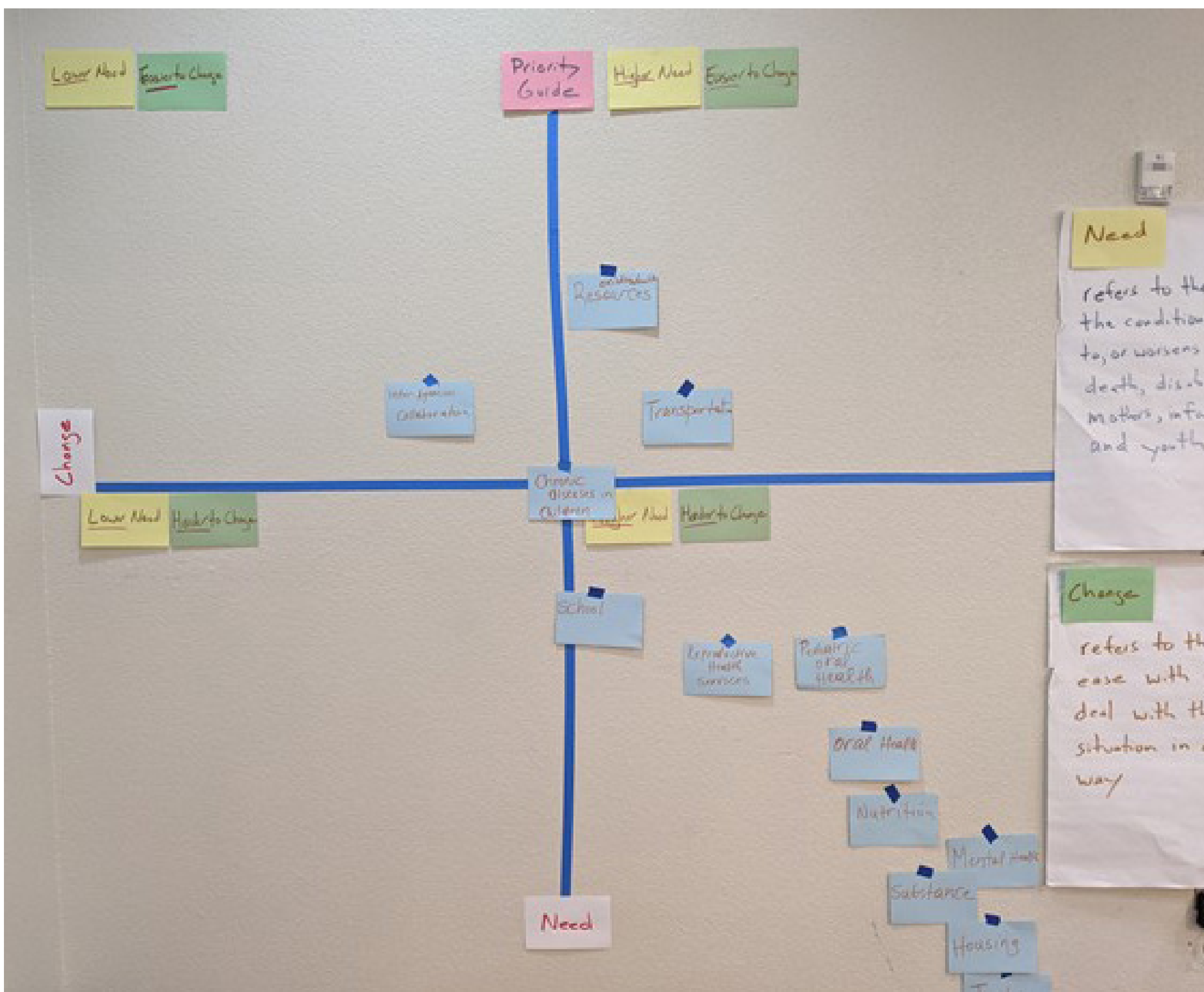


Figure 4: Example Community Forum Prioritization Grid, Cochise County

Modifications for the virtual sessions

Virtual sessions were conducted via a Zoom meeting. Some modifications were made as follows:

Feedback via Zoom chat box

Participants were encouraged to share comments and ask questions by speaking into the microphone at any time and by typing into a chat box. One of the research team members was assigned to monitor the chat and ensure that questions and comments were being recognized and addressed.

Prioritization via Poll Everywhere

Facilitators asked participants questions via Poll Everywhere. This is an interactive audience response system. It was used within the zoom meeting. Participants in the zoom meeting were asked to identify maternal and child health needs.

Poll Everywhere was also used for the prioritization grid. A prioritization grid appeared in the Poll Everywhere screen – the same one that was used for the in-person meetings. Individual participants were asked to place each topic on the quadrant of their choice on the grid. They could only place a topic in one of the quadrants.

Language accommodations

Translation equipment as well as a Spanish-speaking team member were available to translate during the in-person community forums. For the virtual community forums there was one designated Spanish language community forum available for Spanish-speaking participants from across the state.

Figure 5: Community Forum Prioritization Exercise, Pima County

3.3.4 Community Forum Evaluation survey

Immediately after the community forums, all participants were asked to complete an evaluation survey. The survey consisted of 15 questions. The aim was to provide feedback to improve planning of similar events in future. Questions included the role of the participant (parent or member of an organization or both), the county and city where they lived, and the convenience of the community forum (location, time, and facilitation). Appendix 3 provides a summary of findings from the community forums.

Figure 6:

METHODOLOGY OF COMMUNITY FORUMS

Title V MCH Needs Assessment

1 INTRODUCTIONS

Arizona Department of Health Services (ADHS) and University of Arizona (UA) introduced present team members. We explained the purpose of the community forum, logistics, and agenda.

2 PRESENTATIONS

ADHS team provided information on the health status of families and youth in Arizona. UA team presented community perspectives on health issues and services for youth and families

3 BREAK

Snacks and refreshments were provided.

4 GRID ACTIVITY

3-stage interactive activity of identification of local maternal and child health issues followed by facilitated priority setting session for MCH services.

Stage 1

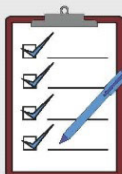
Participants were divided into small groups and each group was asked to identify 5-7 individual issues in their communities.

Stage 2

Facilitation team grouped the individual issues that had been identified into categories.

Stage 3

Very interactive session where the facilitator invited participants to guide him in placing the categories on a two by two prioritization grid on a large board visible to all. The four sections of the grid were labelled along two dimensions; easier/harder to change and of higher/lower need

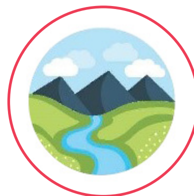


5 EVALUATION

Evaluation form completed by participants to assess participant demographics and roles, convenience of community forum, feedback, and comments.

3.4 Statewide Coverage and Triangulation of Information

We used three data collection approaches:



(i)
River of Life planning tool used at statewide meetings

(ii)
Focus groups and individual interviews used with priority communities

(iii)
Community forums

Every county in the state was included in at least one of these approaches and in some counties all three approaches were used (see Figure 4).

Data from the three data collection approaches were compared to identify similarities and differences in findings. Comparing results from different data collection approaches is called triangulation. Most of the issues that participants talked about were raised in all three components. This strengthens the reliability of the results (the probability that if the study were repeated results would be similar) and the validity of the results (the probability that the results reflect the actual reality). Due to the overlap, in this report we present findings for all three data collection approaches combined. Appendices 3-6 include summary tables of results from each component.

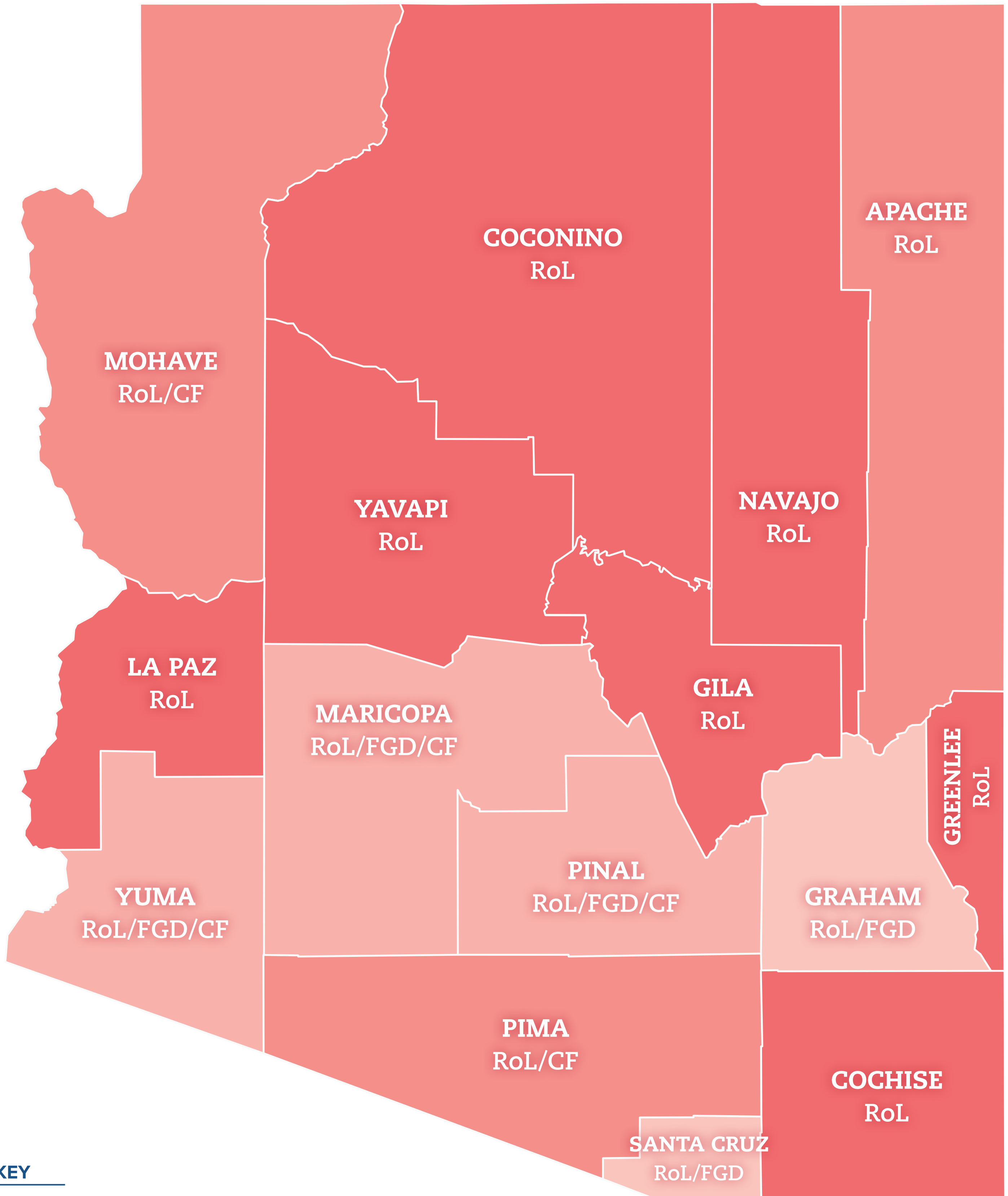


Figure 7: Arizona Title V Assessment: Data Collection Map

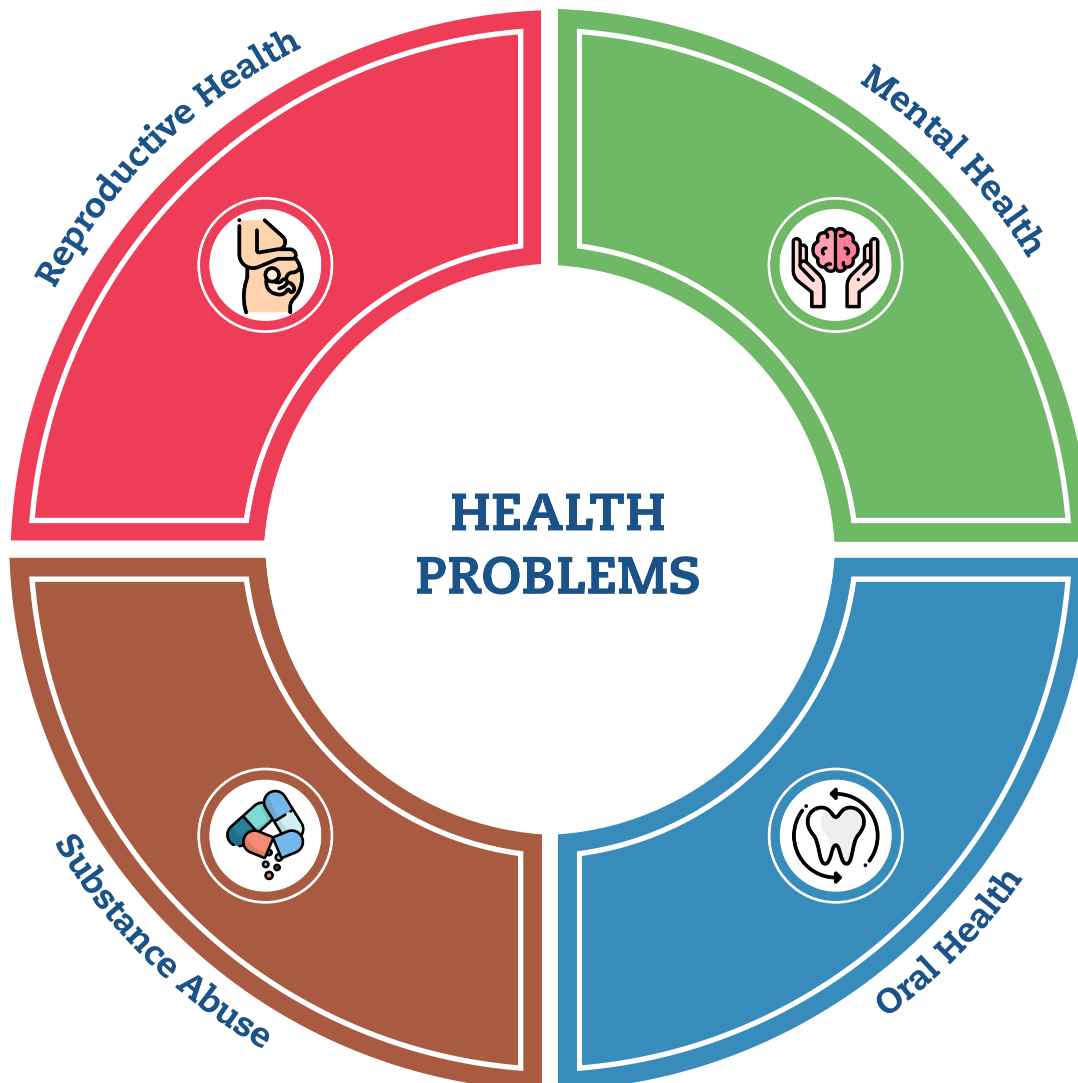
4 FINDINGS

In this section, we present findings from the River of Life planning tool used at statewide meetings, the focus groups and individual interviews, and the community forums. We combine findings from the three data collection approaches because of the significant overlap of data. Health providers and community members across the state identified many similar health issues and similar problems with health services. People from different communities experience these problems in different ways, however. For each topic, we first summarize common themes and then provide more details on the experiences of particular communities. Findings are divided into three sub-sections:

1. Health Problems and Related Health Services.
2. Issues that apply to all Health Services (cross-cutting issues).
3. Other community Services that impact health.

4.1 Health Problems and Related Health Services

The top four health problems that people talked about were: reproductive health, mental health, substance abuse, and oral health. The following sections look at each of these in turn.



4.1.1 Reproductive Health

Reproductive health problems voiced by participants included complications during pregnancy, difficulties managing the newborn, and post-partum depression. In general, participants said they found it difficult to access specialist care before, during, and after childbirth. Those living in rural and frontier communities found it even harder than those in urban and border areas. Many participants discussed the need to have health care services that are located closer to where families live. They want more community-centered programs that provide preventive care across different age groups. They also mentioned the need for policies to provide health insurance for various groups and for different reproductive health services. Some communities have particular reproductive health needs. In the following sections we focus on **pregnant women and families, youth, refugees, and African Americans.**

Reproductive Health Services for Pregnant Women and Families

Participants reported a lack of access to **specialized care** for reproductive health. Although increases in facilities for pregnant women were noted for some counties, the following services were listed as having limited availability across many rural and peri-urban areas:

1. Health care services that manage **disorders in pregnancy** especially for pregnancies that are already complicated with infections, cardiovascular diseases, or hypertensive disorders. For instance: treatment for excessive vomiting during pregnancy; mother-child rhesus blood disparities that could cause harm to babies during pregnancy; and management of hypertensive disorders in pregnancy, especially preeclampsia. The problem is summarized in this quote:

   > ***Pre-natal care doesn't exist in some areas of the state, and for families, in those areas, they are forced to travel to find care.***
   > (Service Provider, First Things First)

2. **Birthing centers** and prenatal centers for mothers and families.
3. **Contraceptive** services including a broad range of options that would improve access to contraception and improve pregnancy prevention among teenagers.
4. **Transportation** support to help families travel to facilities that provide specialized healthcare services for pregnancies.
5. **Post-partum depression** support. Many participants highlighted the limited availability of providers with technical capacity to recognize signs and symptoms of mental health issues:

   > ***We also can't identify prenatal or postnatal mental health needs, like postpartum depression. Birth-to-5 services either don't have any mental health services or very little available. And you have to travel far to get what few there are.***
   > (Service Provider, First Things First)

6. **Culturally appropriate** pregnancy and birth support services, especially for minority groups like refugees:

   > ***Infant mortality is still high in South Phoenix & Marysville. Perinatal support is necessary and should be delivered in a culturally appropriate way.***
   > (Service Provider, First Things First).

Reproductive Health for Youth

> ***It is very difficult to get access for birth control. It is easier to get drugs than contraceptives.***
> (Youth, Graham County)

Participants of all ages spoke of cultural beliefs in many parts of Arizona that make it hard to engage in conversations with adolescents about sexual behaviors or pregnancy prevention. Perhaps related to this, contraception services are hard for youth to access, as reflected in the above quote. Current sex education programs in schools were seen as limited in several ways, including:

- Materials are not relatable to the everyday experiences of youth
- There is an over-emphasis on abstinence without teaching other useful skills including contraception and prevention of intimate partner violence
- Not enough detail is provided
- Materials are not inclusive of all gender identities

Youth thought it was dangerous not providing enough information:

> ***Nobody formally taught us about it. We're just thrown in a situation and have to figure it out as we go. People don't always figure it out the right way…***
> (Youth, Nogales)

Parents find it hard to address these issues and look to schools for support:

> ***My boys are in the puberty phase - having difficult conversations about their bodies and values about sex is important but has not been easy to have. [I] wish schools would help with that, but [I] don't 'trust' all the info [they are] getting out there…***
> (Parent of foster children, Phoenix)

Youth who are also parents face additional challenges. For example, some parenting youth who are in foster care need space and resources to care for their children. These unique situations make it difficult to find foster parents that will commit to taking on teenage parents.

Reproductive Health Services for Refugees

Refugee families face unique challenges in accessing reproductive health services. Reproductive health issues mentioned by refugee women and refugee serving organizations include unmet contraceptive needs; unaffordable fertility care; and female genital mutilation which is common in some countries and impacts a woman's ability to have healthy vaginal births. One service provider suggested a holistic solution to the lack of culturally appropriate care for these women:

> ***[It] feels like we need to come up with the equivalent of a 'doula' program - labor coaches for the [refugee] communities - for any community actually - a doula model or community health worker model for all, would help with expected outcomes.***
> (Service Provider, Refugee Women's Clinic, Phoenix)

Refugee women often rely on family for advice, and their families may have strong cultural beliefs that affect their views about health care. For instance, some women may prefer not to discuss details of their pregnancy because they are afraid this would create an omen that will affect the development of their fetus. Others may choose not to have a caesarean section as this is seen as a sign of weakness in their community. Some refugee families do not understand the concept of birth spacing because their culture does not promote this.

Instead, women are encouraged to continue giving birth until they produce at least one male child. Some women fear their husband will divorce them if they fail to produce a male. Those who are not opposed to family planning may still not accept hormonal contraceptives.

> ***[Women] lean on matrimonial guidance, advice - when it comes to maternal health, some women would rely on their mother's or mom in law or husbands to make decisions about seeking care – [it is the] oldest auntie or mother-in-law who controls this.***
> (Service Provider, Refugee Women's Clinic, Phoenix)

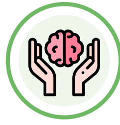
Reproductive Health Services for African Americans

> ***Not having time to heal after childbirth.*** (African American mother, Phoenix)

Participants from the two African American focus groups spoke about the significant stress they experience during pregnancy and childbirth. They have difficulty finding time to rest and rejuvenate after delivery. They thought there were not enough services to support women in their situations. Their experience is summed up in quote above.

Another important issue for this group was that health care providers did not give them enough information or encourage them to make their own decisions on the health and outcomes of their pregnancies.

> ***Doctors make decisions about issues with pregnancies or when a child is sick instead of letting them [families] make an informed decision. The medical staff makes the decisions. They don't let you have options. They don't let you know what is available.***
> (African American Mother, Phoenix)



4.1.2 Mental Health

Mental health was seen as a major health problem that is not being addressed by existing health services in Arizona. When talking about mental health, many people mentioned stress, anxiety, depression, and sleep deprivation. Communities that highlighted mental health issues included parents of children with special health care needs, refugees, African Americans, Youth, and LGBTQ+. Each of these communities gave different reasons for their mental health problems, as described in the following sections.

Mental Health for Refugees

According to service providers who work with refugees, many refugees arrive in the US with mental health problems because of previous traumatic experiences in their home countries and in refugee camps. They may have post-traumatic stress syndrome, depression and anxiety. Once in the US, everyday life can be stressful dealing with new systems for work, health, education and transportation. Many refugees experience discrimination, and this can add to anxiety, depression and stress. An added challenge is that refugees' cultural understandings of mental health issues may be different from those of providers in the US. For example, some languages do not have words for depression or bipolar disorder making it harder to diagnose and treat these conditions. Refugees also said that they have too much work and too little time to relax:

> ***Some of the issues that affect the health of mothers include lack of support for the mothers and the children, no free time to relax and take care of themselves because of too much work at home.***
> (Sudanese refugee, Phoenix).

Mental Health for African Americans

African American participants linked mental health problems with a lack of resources in the community, including housing, schooling and other supports. They said that those with mental illness were being arrested and imprisoned rather than provided with appropriate medical care. One participant said this was "like slavery". Some also mentioned the problem of stigma around mental health in their community. This leads people to be secretive about family members with mental health problems and to avoid seeking care.

> ***I see more young people who are mentally ill. Some of them are babies. But mental health could be resolved with housing, better supports. Baffles me. If not graduate from high school, you will lead a life of crime. And then they build more prisons.***
> (African American parent, Phoenix)

Mental Health for Latinos

Members of Latino communities in Arizona also mentioned stigma around mental health. They said that this leads some members of their community to deny their mental health problems in case people will think them "crazy". Others simply do not know they have a mental health condition. Latino farmworkers also talked of the additional stress they experience from heavy workloads and the need for mental health services.

> ***For mental health, going into the Hispanic communities, mental health has gotten worse because of the stigma. They don't want to talk about it, they say, "I'm not crazy."***
> (Service Provider, Hope Network, Phoenix).

Mental Health for Families of children with special health care needs

Parents talked about the many challenges they faced and how it sometimes felt overwhelming. They have to learn about, and deal with the complex medical needs of their children; find out about screening, diagnosis and treatment; sort out special schooling for their children; and manage other family needs. They said medical providers focus on the medical needs of their children, but the mental health needs of all family members were not addressed.

Some parents explained they had not planned for having a child with special health care needs and they experienced depression when they could not follow their career plans. Others talked of problems in their family relationships and of the financial impact of having a child with special health care needs.

Many felt the need for more respite care, meaning time to look after themselves while someone else took care of their children. Participants in the Yuma focus groups were worried about schooling for their special health care needs children. They said they could not focus on anything else until they were sure their children were happy in school. Two had taken their children out of the public school system because they thought the teachers did not have enough resources to deal with the special needs of their children.

> ***…my own experience…is both my kids have multiple disabilities which is 'total care,'… 24/7 hands on; my husband and I with no (extended) family. I started a mum's group here in Phoenix three years ago…. Because I found myself depressed, anxiety ridden, suicidal, you name it…***
> (Parent of children with special health care needs, Phoenix)

Mental Health for Youth

Mental health came up in all the focus groups with high school students and other youth. Youth mentioned that stress, anxiety and depression were increasing problems for youth that were not being addressed. Similar concerns were raised by service providers from youth serving organizations.

According to youth participants, one cause of stress was that there was not enough time for schoolwork, paid jobs, family lives, social lives, eating, and sleep. This said this led to sleep deprivation. Youth explained how they experience stress from pressures to perform in particular ways from family, school, and peers. Peer pressure and bullying were said to be widespread, starting in Middle School or even earlier. This included cyber-bullying through social media.

> *Depression is a huge topic of adolescent society. There is a lot of bullying and we can't escape it; electronics are used for cyber bullying.*
> (Youth, Pinal County)

Youth participants also said that stress and depression tend to spread within families and communities. They explained that if parents are stressed, children sense this and become stressed. And if young people are depressed, this also affects their parents. In some focus groups it was said that suicide rates were high and increasing. This both reflected and added to mental health problems in the community. In small, rural communities, someone who committed suicide was well known by everyone, so the death had a big emotional impact.

> *Mental health is one of the biggest issues here as well. Many kids I know have committed suicide and have mental disorders, but people don't know how to recognize the signs to help them.*
> (Youth, Graham County)

Youth also talked a lot about the lack of opportunities for career development, jobs and leisure activities:

> *Opportunity-wise, we are limited to attending Cochise College, working in welding or at the prison. It is difficult when no money is available. We are not growing, we are trying to get by, but we are not thriving.*
> (Youth, Cochise County)

Even though youth participating in the study thought mental health was very important, some said their parents downplayed the issue and did not seem to take it seriously. In some cases, youth thought this was related to stigma around mental health, especially in Latino families. This attitude from parents made it even harder for youth to address their mental health needs.

> *Mental health considered minor issue, parents say "you'll be fine" but don't consider it a major problem.*
> (Youth, Cochise County)

In trying to cope, participants said that some youth chose to withdraw from social life while others turn to addictive substances, especially vaping and alcohol. Video games, videos and vlogs were seen as helpful for some youth. Many high school students said how much they appreciated school counselors and teachers:

> *The teachers. They care. They teach you. They have you in class. They can tell your ups and downs. Every teacher knows you. They know you by name. They go above and beyond.*
> (Youth, Pinal County)

Mental Health for LGBTQ+ Community

Participants who identify as gender diverse spoke about the additional mental health challenges they face while finding healthcare and seeking an education. They explained that many organizations like the American Academy of Pediatrics have created guidelines and training materials that doctors' offices and schools can use to provide more appropriate services for LGBTQ+ people. However, in their experience, many organizations do not use these standards nor do they provide training to their staff. As a result, everyday interactions with these organizations are made more stressful for LGBTQ+ people.

Participants spoke of doctors and teachers not using appropriate names and pronouns. Some even show open hostility. This was experienced by participants as traumatic, leading them to avoid seeking healthcare until problems become so severe that emergency services are needed. Participants who were parents explained how it also leads to youth being afraid to go to school. Seeing their youth struggle gave these parents and other caregivers more stress, and they felt the need to raise awareness or demand more respectful care at the doctor's office or school. They added that every year they face a new struggle at the school, when their child enters a new classroom with new teachers. Parent participants noted that accommodations are often easy and inexpensive to implement, the main challenge is merely getting staff to understand how important those accommodations are.

> *We're asking schools for less accommodation that the kids with peanut allergies are asking for.*
> (Parent of trans-gender kid)

However, they said that when parents or caregivers intervene, this places increased attention on the youth and causes them additional stress. Their kids do not want to be treated differently than their peers who do not have issues with gender and sexual orientation:

> *And bullying is terrible. We had kids peeking into her bathroom stall in the girl's bathroom. We tell the admin that it's bad and they say, "well, they're just being curious." I called the police because kids can't be doing that, and the principal wasn't doing anything. And my kid stops using the bathroom and gets a UTI (urinary tract infection).*
> (Parent of transgender child, Phoenix)

Parents of LGBTQ+ children also described the stress youth experience while waiting to secure an appointment. They said that avoidable delays are caused by doctors providing care based on outdated information. They explained that LGBTQ+ youth are more prone to depression and self-harm, so this delay can have a more severe impact on them:

> *Our barrier isn't …finance. It's to get into a doctor. Had to wait a month at [Phoenix Children's Hospital]. No, what made me angry was after years of treatment, [we] suddenly had to go through basic transgender education therapy again in order to get a medical certification letter. [We] had to pay for a repeat 7 months of therapy out of pocket.*
> (Parent of transgender child)

4.1.3 Oral Health

Three key constraints were voiced in relation to oral health:

- A lack of providers especially for children and youth
- Lack of health insurance coverage especially for refugees and undocumented workers
- Lack of awareness of the need for oral health check-ups, which was a big concern of health service providers

Many participants talked about the lack of health insurance for dentists. It was explained that the AZ state Medicaid program, AHCCCS, offered limited coverage for certain groups, such as children and pregnant women, but that not everyone is aware of their entitlements and not all providers accept AHCCCS. Refugees and refugee serving organizations placed a lot of emphasis on oral health as a priority issue.

Oral Health for Refugees

According to service providers for refugee communities in Arizona, dental caries is one of the most important health issues affecting refugees, especially children. They explained that many refugees have had limited or no access to dentists in refugee camps and arrive with acute dental care needs. On arrival in the US, they get support from refugee serving organizations for the first few months. After that, they lose access to dental care. Without dental insurance they find dental care unaffordable. Refugee participants said that some refugees travel outside the US to get dental care. Some even return to their home country, while others go without seeing a dentist at all:

> *The one thing you must write down so they can know that we are really suffering, is that we cannot afford the dentist here. If you have a good job, your work can help you. For us, if you don't have a good education or work you go without fixing your teeth. Not everybody has a good job, one that gives you a dentist…another thing is related to the baby.* ***(Sudanese refugee, Phoenix)***

4.1.4 Substance Abuse

Substance abuse was regarded as a very serious problem by many participants. Communities that expressed specific concerns included youth who reported widespread vaping, African Americans who were concerned about opioids, and Latinos who mentioned drugs and alcohol. Participants emphasized that there are only a few “anti-drugs” groups and services, and that some are helpful while others are ineffective. Youth participants mentioned that constant repetition to stay away from harmful substances and scare tactics are ineffective approaches to prevent substance abuse.

Substance Abuse for Pregnant women

Many participants, including service providers, were concerned about drug use among pregnant women and the lack of support services for them. They reported concerns that mothers who are addicted to drugs are often victimized and arrested for endangering their fetus. They observed that this discriminatory practice prevented addicted mothers from getting the help they need to stay healthy and keep their babies healthy:

> *There is no safe place a mother who is addicted can go for treatment if she is pregnant, they’ll just arrest her for fetal endangerment. We need more programs to support pregnant & addicted people.*
> ***(Service Provider, First Things First)***

Substance Abuse for Youth

Youth participants thought that substance abuse was so common because it was so easy to get drugs. They said that many learn about drugs and where to get them through social media. They do not see it as a bad thing because in some cases their families also use drugs and alcohol. They explained how being able to smoke or drink with their older family members was seen as a tradition, similar to a quinceañera, where they transition from childhood into being an adult. Adolescents also reported increasing prevalence of vaping among their peers. They suggested that interventions that aim to prevent initiation of e-cigarettes should begin before middle school.

> *Kids use them in the school bathroom although there are posters against vaping all over the school, in the bathroom and cafeteria.* ***(Youth Participant, Safford)***

4.2 Health Services: Cross-Cutting Issues affecting Access

In this section we focus on issues that cut across all health services in Arizona. These issues were all mentioned many times by health care providers and users of health services. They include **availability of services, access to services, affordability of services, information about health and health services, discrimination by health care providers and continuity of health services over time.**

Availability of Health Workers
Accessibility: Transportation
Affordability: Health Insurance
Health Information
Discrimination from Health Providers
Continuity in Health Services

CROSS-CUTTING ISSUES

4.2.1 Availability of Health Workers

Health care workers and community members highlighted the lack of health providers, especially in rural and frontier communities. Obstetric services for pregnant and birthing mothers, dental services, services for children with special health care needs and mental health services were often mentioned as not available in small towns and villages, forcing people to travel long distances for these services. Some participants said there used to be more providers in rural areas, but that services were declining.

Service providers explained how it is hard to encourage health workers to stay in remote areas. Even if there are incentives, they are usually time limited:

> ***There are incentives to work in underserved communities, but there are many who work there for the minimum required number of years but don't become invested in the community, so they leave as soon as they get the benefits.***
> (Service Provider, First Things First)

4.2.2 Accessibility: Transportation

Based on comments from participants, transportation was a strong determinant of access to maternal and child health services. Several participants explained that low-income families rarely own their own cars, and they cannot afford to pay for taxis, so they rely on public transportation, friends or neighbors for help. Although distances may be further for those in rural areas, the limited availability of public transportation was mentioned by participants in urban areas as well. Based on the experience of participants, people often fail to get to an appointment on time or miss work or childcare time because they are waiting for the bus. It was also said that some areas have no bus services at all. This issue was voiced frequently across many focus groups, especially those with Latinos and youth.

> ***Transportation to the clinic [is a problem]. We have to find someone to take us to the clinic. We don't have a car. In the children's school they require that the children are vaccinated before they can enroll. They have to have dental exams as well as a physical to enter. Including a TB test and other vaccines. The clinic is 13 miles from here.***
> (Participant, Cochise County)

4.2.3 Affordability: Health Insurance

> ***Much of our population is uninsured or underinsured, so they aren't able to afford services.*** (First Things First, Phoenix)

Lack of health insurance was high on the list of priority health issues for participants from many communities because it prevents people from accessing needed services. Because they do not have health insurance many people choose not to seek care or end up with the wrong care. Four issues were highlighted:

- Limits on eligibility to AHCCCS related to income
- Limits on eligibility for AHCCCS related to immigration status
- High cost of private insurance
- Specialized services not being covered by health insurance - whether AHCCCS or private

In Arizona, the Medicaid program of health insurance for low-income people is called AHCCCS. The eligibility criteria for AHCCCS was experienced by many participants as too restrictive. Several participants described how they earn a little bit too much to qualify for AHCCCS but not nearly enough to buy private insurance. This meant that they had to choose between having a job that would pay the bills or leaving their job so that they could qualify for AHCCCS health insurance and get the health care they need. This issue was often raised by refugees and people from Latino communities. These communities sometimes also face eligibility issues due to their immigration status. Also, participants from families with children with special health care needs and families with members who identify as LGBTQ+ need specialized care that may not be covered by their health insurance.

Health Insurance for Latinos

Several participants from Latino communities talked about how they chose not to work or have very low paid jobs just so that they can get government health insurance under AHCCCS:

> ***It is sad but it's better to have a low paying job so that we qualify for AHCCCS instead of making more money and having to pay so much for receiving medical care.***
> (Latino parent, Yuma)

Participants explained that those who are undocumented are not eligible for AHCCCS no matter how much they earn. They said that in some families there are certain members who are eligible for AHCCCS while other are not. For example, there were families where the children were born in the US, so they have AHCCCS, but the parents do not. According to participants, some people who are not eligible for AHCCCS try to get private insurance but struggle to maintain premiums and co-pays:

> ***We paid 200 dollars per month for the insurance, but we still have to pay a co-pay. Bi- weekly, we pay the insurance, but it's not covering enough. My husband said we might as well get divorced because then the premiums will be lower and cheaper.***
> (Farmworker, Cochise County)

Another option that was mentioned was to cross the border into Mexico in search of affordable health care:

> ***People avoid going to the doctor, they often self-prescribe medications. Some people have diabetes and do not go to the doctor. Instead, they have family from Mexico that share their medications. Due to lack of insurance, people share medications with their family members.***
> (Service Provider, Hope Network, Phoenix)

Health Insurance for Families with children with special health care needs and LGBTQ+

Focus group participants explained how families with children with special health care needs and families with members who are LGBTQ+ often struggle to find doctors who can treat their and their

children's complex medical issues. They may need several different specialists to treat the complicated health problems of one child. Sometimes, they find the special doctors they need are not covered by their health insurance.

> ***We have parents that show up asking, "well where can we get this taken care of, or that" and we give recommendations but then there's the insurance part that makes it more complicated. You can say, "well our doc has an opening" but it doesn't help if they don't take the insurance.***
> (Service Provider, Phoenix)

Participants explained that insurance coverage is complex. Even AHCCCS has several programs with different coverage:

> ***AHCCCS isn't just one thing. Different plans work better with different pharmacies & providers. Sometimes you can switch plans, but knowing which plan is best for your medical condition. Sometimes you can ask online for word of mouth as to which is best. Comorbidity is an issue, though.***
> (Parent of a transgender child, Phoenix)

4.2.4 Health Information

(There are) great resources in our community (but) no cohesive way to understand them and connect families to them.
(Parent of child with special health care needs, Phoenix)

According to participants, information is obtained from health providers and community organizations, from family and from social media. However, many participants talked about the problems they faced in finding out about health services. Others talked about situations where they were provided with incorrect information or they were referred to the wrong resources.

Participants revealed how difficulties are faced at every stage along the health care seeking journey: first, knowing what health care you need; secondly, knowing what services and providers are available; thirdly, knowing whether what is available is covered by your health insurance; and finally, working out how to get to the service at a convenient time and how to arrange childcare or time off work. Participants find that the information needed to navigate these systems is not readily available and they must seek it out. They also noted a lack of coordination between services:

> ***Many struggling families don't know what they qualify for, and individual services don't recommend each other. For instance, if you qualify for childcare, they don't tell you you're more than likely qualify for WIC.***
> (Service Provider, First Things First, Phoenix)

In general, participants found the health system to be complicated and fragmented. The following communities face particular difficulties:

Health Information for Refugees

Refugee community service providers reported that refugees often face language and cultural challenges in understanding how the various systems of health care provision, health insurance, transportation and childcare operate in Arizona. Refugee participants acknowledged that translation services are sometimes available but, in their experience, they may not provide exactly the right language or dialect.

> ***The written stuff is good for those who can read, but for those who cannot read, and must rely on the interpreters, it is not good. They bring you someone who speaks Arabic, but it is not our Arabic, we don't understand that…they bring those who speak Iraqi and Syrian Arabic. They need people from different countries especially when they call the 1-800 translation number.***
> (Sudanese refugee, Phoenix)

Staff from refugee support organizations reported that they help refugees to navigate the health system when they first arrive. For example, one service provider in Tucson described how, within the first 30 days of arrival, refugees are provided with a comprehensive health screening.

Their organization then assists in referring them to needed services, even accompanying them if necessary. They explained that it is not only the health system but also the transportation system that can be experienced as daunting for new arrivals. Another service provider for refugees in Phoenix explained that it is not only practical logistics but also cultural translation that is needed:

> ***Cultural Health Navigators (are) employees that (we) put in place to help the patient navigate the values aspect of the health care system – (their) main role is to coordinate a patient's health care journey - with a patient's insurance eligibility, "you have full health coverage" - helping them understand what this means - and make sure they are advocating for themselves, and help them understand how to actually physically - get to their doctor appts: taxi, bus, will escort them to services (imaging, pharmacy, etc.) - so patients leave with everything accomplished.***
> (Service Provider, Women's Refugee Clinic, Phoenix)

Health Information for Families with children with special health care needs

Parents of children with special health care needs were especially concerned about getting access to screening and diagnostic services because a correct diagnosis is needed in order to get the proper health care services for their children. Some participants still did not have a diagnosis for their child's condition. Others found out needed information almost by accident:

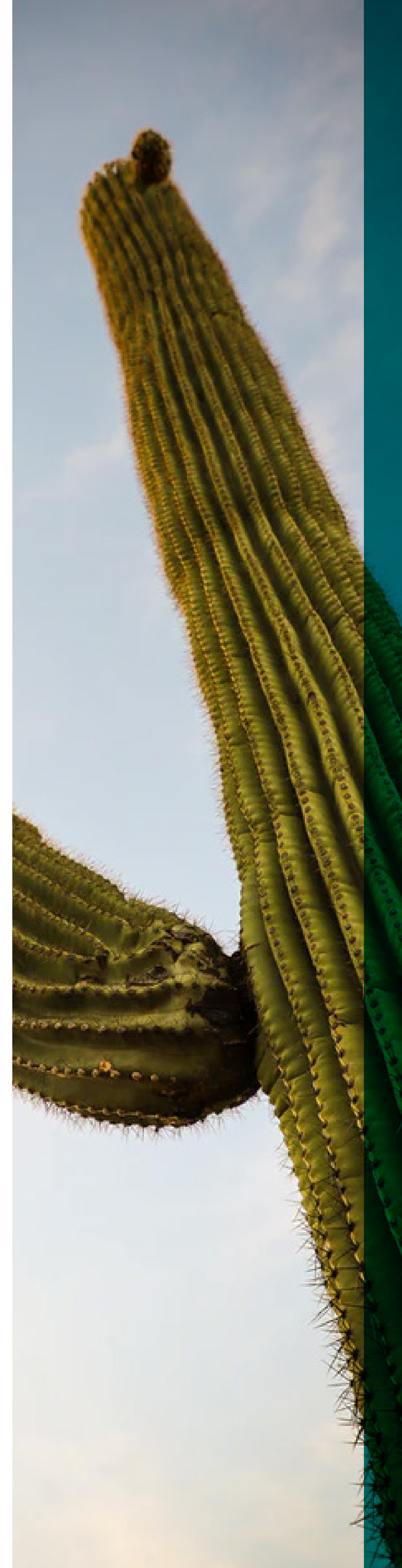
> ***You stumble upon (services) – from specialist, friends, internet. No one story is the same. (It's) not like everyone goes to this person and they help you. Before our daughter had a diagnosis, we didn't know how serious (her condition was). We just thought 'we're always in the hospital'***
> (Parent of child with special health care needs, Phoenix)

Participants said that once the health condition is known, finding out what providers and services are available presents another challenge:

> ***Many times, I've gone to ask about a service and I get sent to another place, and that place sends me to another place, because people don't have access to proper information.***
> (Parent of child with special health care needs, Yuma)

Some parents suggested that family navigators were needed to help families with children with special health care needs because dealing with the health system is so complex for them.

> ***My wife and I talk a lot about family navigators. We were good at navigating our son's journey. Others don't have the skills to navigate through the system. (Families should have) assigned to them a family navigator who can connect them. We have our son at ASU, we felt like we were the first family. Can't be right. How come we had to rediscover everything for the first time?***
> (Parent of child with special health care needs, Phoenix)



Health Information for LGBTQ+

Participants from the LGBTQ+ community said their families have difficulty finding respectful care in their communities. They explained how they rely on word of mouth from other members of the community or from advocacy organizations in the state to know where they can turn for vital services, such as gender care services. They pointed out that there is no state database for the public to know which healthcare providers have appropriate services, so members of the LGBTQ+ community are forced to find out this information through trial and error. Similarly, they rely on community members to help navigate the challenging system of insurance to know which plans cover what services and where they are accepted.

Health Information for Foster Families

Parents of foster children explained that children entering foster care are likely to require more healthcare services than the general population. Knowing how to identify needs and how to find services is a big challenge for them. Participants that provide foster care or work with foster parents described the many ways they find information on how to get care for their children. In their experience, foster care case managers and licensing agencies can provide information, but the quality depends on the experience and willingness of staff. Staff often do not stay in post for long so they may not have much local knowledge and experience. These foster parents often relied on word of mouth from other foster parents. Sometimes they find support groups for foster parents facing similar health issues and needs.

> ***At a foster care agency, the quality of health information they get is only as good as the family's licensing agent. If they don't care or don't know, foster families are on their own. Licensing agents have heavy turnover [of staff], too, so that knowledge is lost with them. People who care and fight for families burn out for lack of resources. Frustrations for foster families means fewer keep providing care.***
> (Foster parent, Pima County)

4.2.5 Discrimination from Health Providers

Discrimination against Non-White and English as a Second Language Communities

> ***Sometimes people are very racist and refuse to help us. If we do not speak English, we will not be helped.***
> (Participant, Cochise County)

Participants from refugee, migrant farmworker, Native American, immigrant, and undocumented communities described how discrimination is a common issue while seeking healthcare. They spoke about cases where the health care provider had racist views and used racist language. Some also had experience of facilities where providers were not ready to provide care to people from different ethnic groups. For example, they found that care was not provided in an appropriate language or no-one was trained to understand health beliefs and practices from other cultures.

Discrimination against the LGBTQ+ Community

Participants from the LGBTQ+ community described traumatic experiences while seeking care even at common places like the dentist or urgent care clinic. They described how providers were often dismissive, disrespectful, mocking, or threatening:

> ***LGBT+ people take a gamble when they go in to get care. The state needs to do something to make it less dangerous. Policy changes [are needed]. Insurance needs to be able to have a search function for providers that are listed as LGBT+ friendly indicating they have anti-discriminatory practices. AHCCCS could add a link.***
> (Parent of a transgender child)

Participants explained that, even if they do not intend to discriminate, providers are often unfamiliar with the specific healthcare needs of their LGBTQ+ patients and some are unwilling
to learn:

> ***The doctors don't have any idea how to chart when it comes to transgender people, even doctors who would be supportive but just haven't been given the education. … it will contribute to their confidence. They don't mean to be disrespectful because they just don't know.***
> (Parent of transgender child, Phoenix)

According to participants, this causes many members of the LGBTQ+ community to avoid seeking care even when it is urgent:

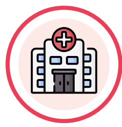
> ***The emergency room is the most notorious at least in my experience. If they had just a little primer on how to be respectful... In my experience you turn into a freak show and there's thirty doctors in there for a simple emergency and they're looking at you and asking and observing. At least for me I don't want to go- I'd have to be dead and then I'll go to the doctor. That's how intense it can be in certain services.***
> (Transgender participant, Maricopa County)

Participants reported that children entering the foster care system are more likely to identify as LGBTQ+ than their peers. However, they voiced concern at the lack of screening for foster children for sexual orientation or gender identity by state agencies. In their experience, this meant that youth were often placed in foster homes that did not accept the youth or where family members reacted violently with them. Participants pointed out that the

Department of Child Safety has statements on being supportive of all communities, but in their experience, individual staff were often unwilling to ask about or advocate for the LGBTQ+ youth they are assigned to support.

> ***There's no [gender or sexual orientation] identification so they get to group homes or foster homes where they're bullied. Maybe they tell their case manager or therapist, but that information should be provided for everyone, it should be in their paperwork.***
> (Foster parent, Maricopa County)

Foster parents who are LGBTQ+ talked about the discrimination they experienced. They said that more and more agencies were stating religious objections to allowing LGBTQ+ families to foster or adopt. At the same time, they explained that demand was going up as more children are entering the system and need homes. According to participants, some LGBTQ+ people who want to be foster parents have had to seek out specific judges within the state to grant them adoption services. Judges are not required to agree to adoption by gay and lesbian parents and some refuse to.



4.2.6 Continuity in Health Services

Having the same doctor in the family has helped build trust
(Youth with Our Family Services, Tucson)

Based on focus group discussions, participants clearly value having the same doctor, nurse or other care provider over many years because this helps to build trust and familiarity with the provider. Yet many participants said they had to keep finding new care providers for themselves or other family members. Reasons given were that their care provider had changed jobs, or the provider was no longer covered by their health insurance. Participants who were parents explained that some programs target certain age groups and so their children had aged out of the program and had lost access to the service. Participants also reported that some health programs had ended because the funding had run out. Whatever the reason given by participants, this lack of continuity, had meant that they had lost access to health services they once had. This resulted in them losing confidence in the health care system. Communities affected by continuity included families with children with special health care needs, youth and foster youth. Health service providers were also concerned about continuity issues, particularly the high turnover of health staff:

> ***Home visitation is concerning, mostly because of staffing. It's hard to recruit and keep quality staff, which makes building a relationship and comfortability with community difficult.***
> (First Things First, Phoenix)

Continuity for Families with children with special health care needs

Participants with children with special health care needs reported having to see health care providers often. They said that continuity in staffing was very important both for them and for their children. One participant explained that for some conditions, like autism, the child finds it hard to adapt to new people. Another added that, for the parents, they need to know that the health care provider is reliable and will be available when needed. One participant chose not to use a service because she was not sure if it the care would be continuous:

> ***Mercy Care (a non-profit) called me the other day "are you interested in this program where you'll have a care coordinator?" And I said no because in my experience they change personnel every time... if I have confidence in the person, I would say yes...I have to confidence because we are going to rely on each other.*** (Parent of child with special health care needs, Phoenix)

Parents of children with special health care needs were especially concerned about the decline in available services as their children got older. They mentioned several service organizations providing excellent support up to age five years, but they experienced much less support during grade school, and even less when their children turned 18. One participant commented that when a child with special needs has to change provider the new provider may know nothing of their condition, so parents have to start all over again.

Continuity for Youth

"Aging out" of services was also mentioned by youth participants as well as by parents of foster youth. Even if services are available for older ages, the eligibility requirements may change, making it hard for youth to figure things out.

> ***(There is) ever changing eligibility for services - particularly at transition - youth have to learn a whole new set of 'rules' to gain services.***
> (Service Provider, Onward Hope, Phoenix)

Health care providers said some youth programs ended because the funding ran out. An example was the Head Start program in Pinal and Pima counties. The loss of this holistic pediatric program was described by one participant as "devastating" and left the towns of Payson and Globe with no comparable programs. Another staff commented on lack of follow-on services after pediatric screenings:

> ***There are lots of screening programs, but not many services afterward. It's not helpful to detect health challenges without providing support to address them, it's frustrating.***
> (Service Provide, First Things First, Phoenix)

4.3 Community Services that Impact Health

Participants mentioned several factors that influence their health and their access to health services in their communities. These included **childcare** services that enable parents to work and access health care; good quality **housing** that allows people to practice good health and hygiene in the home; access to **good nutritious** foods in the community; and access to **safe places for work, leisure and sport,** for all ages.

4.3.1 Childcare

The need for safe, affordable childcare was voiced frequently by participants in this study. Common themes that emerged from the data include:

- There are many quality programs in the state that provide needed daycare and after school care for families. However, these services are more available in urban areas. Many **rural communities** have no established childcare services
- Even if services are available, families are often **unaware** of the services in their area or they do not realize they may qualify for assistance

- Many people find they need childcare in order to **work.** But the income from their job puts them above the levels needed to qualify for public childcare assistance. Thus, they no longer qualify for the very childcare support that enables them to work. Areas that have voted to increase the minimum wage have experienced this catch-22 even more than others
- There is a lack of private care services that provide state-regulated **safety standards**
- The lack of available childcare services makes it hard to attract and keep **health care providers** in rural areas.
- Childcare is also essential for families seeking **healthcare.** State insurance plans provide transportation for families unable to reach their health appointments. But they have strict policies on only transporting the child obtaining care. No other children are allowed. Parents therefore need to arrange childcare for any other children under their care.
- The lack of affordable, state-regulated care means that families often turn to alternative methods, such as leaving the child in the care of family or strangers. It was said that some parents were forced to look over social media to quickly find care accommodations, so they are able to work. One provider related:

> ***Parents often have to put kids in unsafe childcare situations to be able to work. Sometimes strangers in unregulated, informal daycares.***
> (Participant, First Things First)

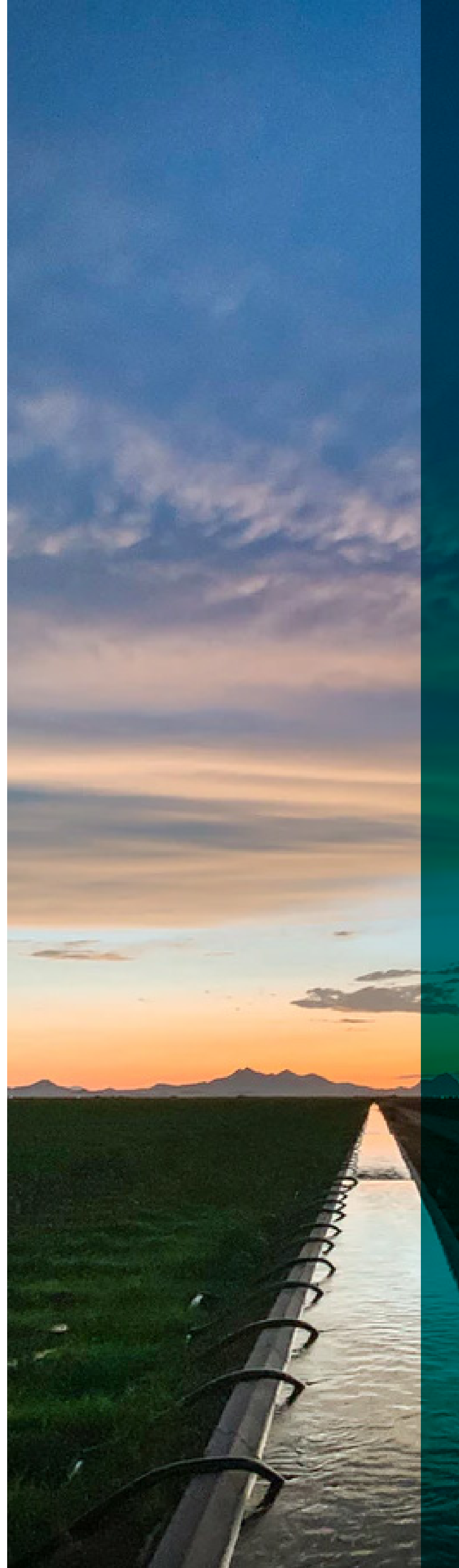
4.3.2 Housing

Homelessness and the high cost of housing were often mentioned, especially by participants from African American and Latino communities and by organizations serving youth. They reported that, in many areas, there is not enough good quality housing. People are forced to live in poor-quality houses and may face a constant threat of eviction from their landlords. This increases stress for the families:

> ***No matter where, the lack affordable housing is causing major issues for families and has a dramatic impact on health. Many families are being priced out of their homes and don't have anywhere to move to that also has work.***
> (Service Provider, First Things First)

According to service provider, the housing stock appears to be declining even as demand for housing is increasing:

> ***In the last 10 years, the amount of housing and transitional housing and shelter has gone down to about 20% of what it was. Housing/shelter is of great benefit to these adolescents but has declined.***
> (Service Provider, OneNTen, a non-profit working with LGBTQ+ youth)



4.3.3 Food Services

Some of the issues that came up in the discussions around food and health include:

- Lack of access to affordable, healthy foods
- Lack of awareness around good nutrition
- Lack of time for cooking and eating
- Reliance on fast-food even when it is not the preference

Health service providers talked of "food deserts" meaning areas where people have to travel more than 5 miles to buy fresh fruit and vegetables. This is a big problem for those without transportation and for the elderly.

> ***We have a whole part of our county that doesn't have access to a grocery store. It's a food desert and people are only able to eat what they can get."***
> (Participant from First Things First, Phoenix)

Youth mentioned that fast food is often the fastest and cheapest option during the school lunch time.

> ***We don't have enough time for lunch. When fast food restaurants are very busy during high school lunch time, we "hustle" to get food or resort to a gas station."***
> (Participant from Safford High School, Safford)

4.3.4 Environmental Health Services

Environmental health hazards were a common concern, especially for farm workers and others residing in rural locations. Participants were most worried about:

- High pesticide use
- No paved streets
- No garbage collection
- Stray dogs

Farmworkers voiced concern about the pesticides that are used in the crops they work with. Others were worried about burning trash:

> ***Since we have no regulations here, sometimes we burn our trash and many times we are unaware of the things that we are lighting on fire. The trash may have contaminants that can later cause problems.***
> (Farmworker, Cochise County)

Participants also worried about their kids getting bitten by one of the many stray dogs. This is related to the lack of access to safe infrastructure. There are few safe spaces for children to play. People living in urban industrial locations were worried about industrial pollution. They thought trash on the streets had harmful chemicals. Trash services are expensive and often not provided by landlords. They said the authorities did not take this problem seriously.

> *Recycling has not worked, there is a lot of plastic trash around the communities. We see more pollution and contamination from the trash. The governor is not paying attention to this issue.*
> ***(Service Provider, Hope Network, Phoenix)***

5 RECOMMENDATIONS FROM PARTICIPANTS

Participants came up with many suggestions and recommendations in relation to the problems that they identified. Many times, the same suggestions came from different communities. Here we summarize the most common recommendations.

1. **Service provision needs to be more holistic,** shifting from a focus on individual medical conditions to a focus on the person, family and social context. This will involve increased provision of **mental health** services and services that **continue over the life course** especially for children with special health care needs.
2. **Navigators** are needed to help families navigate the health services. This includes: (i) finding out about health conditions and services; (ii) how to access health services; (iii) eligibility for health services and health insurance, and (iv) how to minimize risks of discrimination.
3. **Information hub** is needed – the same information on health and health services should be available in all government offices (schools, libraries, clinics, police station etc.)
4. Health services should be **available** in community centers such as schools, libraries, churches
5. There should be better **coordination** across services so that families can apply with one set of forms to access multiple services they need
6. Community members should **participate** in planning and provision of health services. For example, there should be a community health worker advisory board to advise government
7. **Quality of services** needs to improve in two key areas:
   (i) increasing **motivation** for health care workers so that they do not keep leaving their positions, particularly in rural, frontier and other under-served areas
   (ii) increasing **training** of health personnel in how to communicate respectfully within the patient's cultural understanding; in **treatment** of children with gender care needs; and in trust building especially with those from under-served communities.
8. AHCCCS health **insurance limits** need to **be extended** so that working people on low incomes can have access health care.
9. **Dental care** for adults should be included under AHCCCS and should be affordable to those not on AHCCCS.
10. **Child-care** services need to be more widely available so that parents can work and get access health care services.
11. **Health education in schools needs to be relatable.** Students are less interested in dire warnings and statistics, and more interested in personal testimonies of people like them.
12. **Schools and communities** need to provide more opportunities and career support to youth to address mental health and substance abuse issues.
13. Training and screening for **foster families** should include accommodations for gender and sexual minorities to ensure their safety and health care needs are met in their new homes.
14. There should be more parenting classes and foster care training to promote healthy **family relationships.**
15. **Public transportation** services should be expanded.

APPENDIX 1: SUMMARY FINDINGS FROM RIVER OF LIFE DIAGRAMS

Priority Issues Raised:

- Access to mental and behavioral health services
- Access to pre-conception and pre-natal care, especially for women in rural communities
- Funding for health services and health insurance
- Care for substance abuse across the life-course
- Health literacy and health promotion services
- Prevention of teenage pregnancies

Sample from River of Life Framework Analysis Table

(Full table is available on request. Please email Priscilla Magrath at pmagrath@email.arizona.edu)

APPENDIX 2: SUMMARY FINDINGS FROM FOCUS GROUPS AND INDIVIDUAL INTERVIEWS

Table 1: Health Problems

Health Problem	Refugees	African American	Latino	FCSHCN	LGBTQ+	Youth	Providers
Reproductive health	■	■	■			■	■
Mental health		■		■	■	■	■
Oral health							■
Substance abuse						■	

Note: shading indicates the issue was raised at least 3 times per focus group or interview for that community, on average

Table 2: Health Services: Cross-Cutting Issues Affecting Access

Health Problem	Refugees	African American	Latino	FCSHCN	LGBTQ+	Youth	Providers
Availability of providers				■	■		■
Transportation			■				■
Health insurance			■	■	■		■
Information	■	■	■	■	■	■	■
Discrimination	■	■	■		■	■	■
Continuity	■	■		■			■

Note: shading indicates the issue was raised at least 3 times per focus group or interview for that community, on average

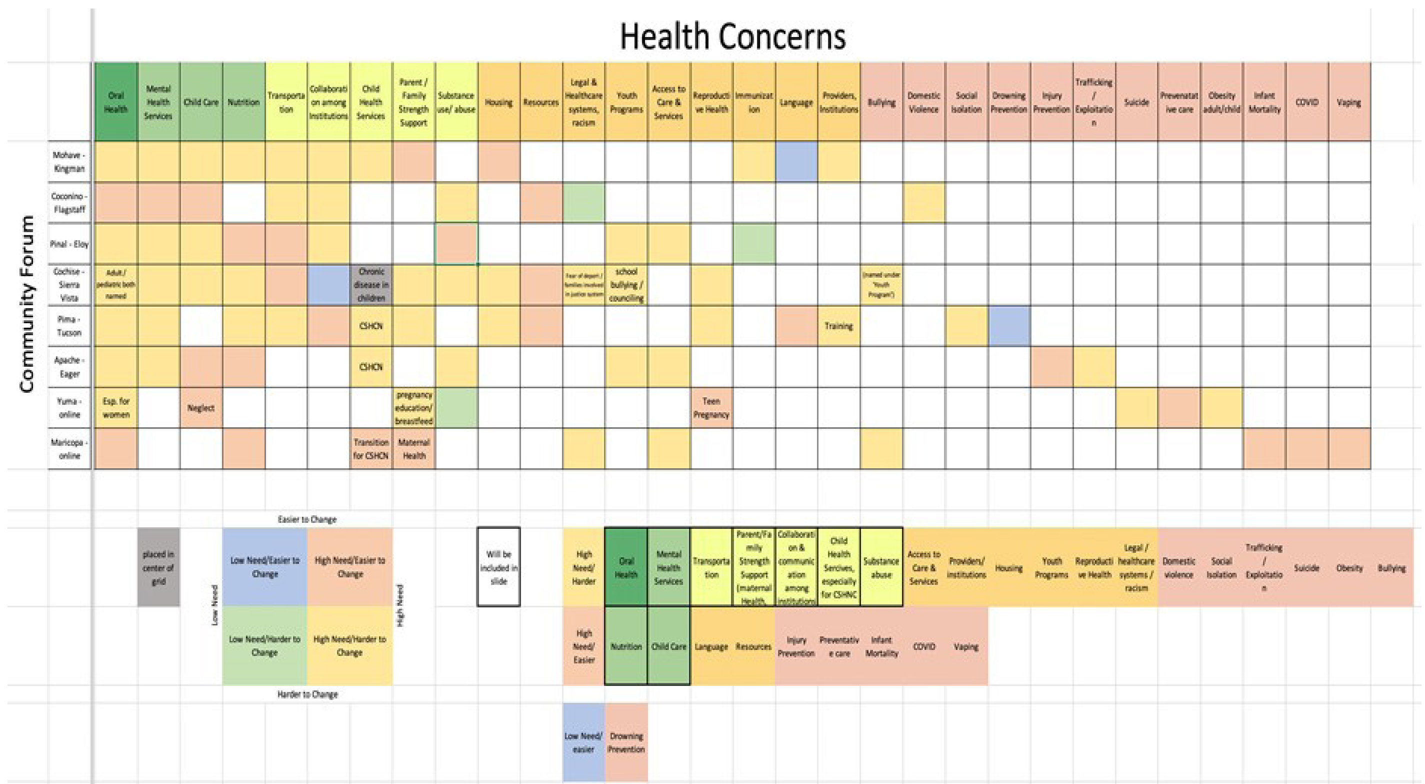
APPENDIX 3: SUMMARY FINDINGS FROM COMMUNITY FORUMS

Priority Issues Raised

Priority	Health Concern	Proportion of Forums
Higher Need/Harder to Change	Oral Health	All
	Mental Health	Almost all
	Transportation	Most
	Parent/Family Education/Support	Most
	Collaboration among Institutions	Most
	Child Health Services esp. for those with special health care needs	Most
	Substance Abuse	Most
Higher Need/Easier to Change	Nutrition	Almost all
	Child Care	Almost all

Summary Table: All Forums

(Tables from individual forums are available on request. Please email Priscilla Magrath: pmagrath@email.arizona.edu.)



APPENDIX 4A: FOCUS GROUP QUESTIONS FOR PRIORITY COMMUNITIES

Please use Consent Form for Focus Groups for all focus group participants.
Please follow the Instructions and Checklist for focus groups.

Date of focus group: ____________________***Location of focus group****:* ___________________________
Was the Focus Group recorded? *YES / NO* ***Filename of recording****:* _________________________
Name of facilitator*:* _______________________ ***Name of notetaker****:* _____________________________
Description of focus group (communities included):____
Regions Represented in focus group*:* ____

Prompts:

1. **Thinking about the health of mothers, children and adolescents in your communities, what are the most important issues?** (record all issues that are mentioned)
   Follow-up: who in the community is most affected by these issues?
   (children, youth, pregnant mothers, new mothers, mothers with many children, other caregivers)
   Follow-up: What do you think are the causes of these issues?
   Please specify causes separately for each issue.
   Follow-up: Over the past 5 years, have these issues been getting better or worse? Why?

2. **Where do families go for information and services related to the health of mothers, children and adolescents?**
   (Prompt: family, neighbors, schools, churches, pharmacies, clinics, web sites, other?)
   Follow-up: how would you describe the information available?
   (Prompt: Acceptable reading level, translated materials, culturally appropriate, easy to understand, easy to access, helpful, factual, sufficient?)
   Follow-up: How would you describe the services provided?
   (Prompt: easy to access, helpful, sufficient, respectful)

3. **What resources, programs or services are working well**?
   Follow up: Why are they working well?
   Follow-up: Can you describe any resources, programs or services that your community benefited from in the past, that are no longer offered?
   Follow-up: Do you know why they are no longer offered?

4. **What resources, programs or services are not working so well?**
   (Prompt: What challenges do people face in using existing services?)

5. **What suggestions do you have for improving the health of mothers, children and/or adolescents?**
   (Prompt: What services or information are needed but are not being provided?)

6. **Is there anything else you would like to say about the health of mothers and children?**
   (Prompt: What are the concerns specific to your region/community?)

APPENDIX 4B: INTERVIEW QUESTIONS FOR SERVICE PROVIDERS

Please use Consent Form for Individual Interview
Date of interview: _________________________ ***Location of interview****:* _________________________
Was the interview recorded? *YES / NO* ***Filename of recording****:* __________________________
Name of interviewer*:* _______________________ ***Name of notetaker****:*
____
Name of interviewee: ____
Organization where interviewee works*:* ____
Position of interviewee in the organization*:* ____
Counties where this organization works: ____

Prompts:

1. **Describe the current work that you do related to maternal, child and adolescent health?**
   (Prompt 1: What communities of women, children and/or adolescents do you work with?)
   (Prompt 2: What types of services do you provide to women, children and/or adolescents?)
   Follow-up: Over the past 5 years, have these issues been getting better or worse? Why?

2. **What are the most important issues affecting the health of mothers, children and adolescents in the communities you work with?**
   Follow-up: who in the community is most affected by these issues?
   (Prompt: children, youth, pregnant or new mothers, mothers with many children, caregivers)
   Follow-up: What do you think are the underlying causes of these issues?
   Follow-up: Over the past 5 years have these issues been getting better or worse? Why?

3. **Where do the families you work with go for information, resources and services related to the health of mothers, children and adolescents?**
   (Prompt: family, neighbors, schools, churches, pharmacies, clinics, web site, other?)
   Follow-up: How would you describe the information available to these communities?
   (Prompt: Acceptable reading level, translated materials, culturally appropriate)
   Follow-up: How would you describe the services provided?
   (Prompt: easy to access, effective, respectful, timely, sufficient)

4. **What resources, programs or services are working well for the communities you work with?**
   Follow up: What are some of the reasons why they are working well?
   Follow-up: can you describe any resources, programs or services that these communities benefited from in the past, that are no longer offered? Why are they are no longer offered?

5. **What resources, programs or services are not working so well?**
   (Prompt: What challenges do people face in using existing services?)

6. **What suggestions do you have for improving the health of mothers, children and/or adolescents in the communities you serve?**
   (Prompt: What services or information are needed but are not being provided?)

7. **We would like to invite representatives from x community to participate in a focus group. What would be the best way to reach them and have them participate?**

APPENDIX 5A: ADULTS FOCUS GROUP DEMOGRAPHIC SURVEY RESULTS

Participants in focus groups were asked to complete a demographic survey. This table presents results from the surveys completed by adult participants.

Contextual Factors	N=57
Mean Age	40 years (S.D.13.5) Min: 19 Max: 74
Survey Language	(n) %
English	(39) 68%
Spanish	(18) 32%
Gender	
Female	(50) 88%
Male	(4) 7%
Non-binary Transgender (female to male) Transgender	(1) 2% (1) 2% (1) 2%
Sexual Orientation	
Straight	(45) 90%
Bisexual Lesbian or Gay	(2) 4% (2) 4%
Queer	(1) 2%
Relationship	
Married	(34) 60%
Single	(8) 14%
Have a partner/boyfriend/girlfriend	(4) 7%
Widowed	(4) 7%
Domestic Union/Partnership Separated	(2) 4% (2) 4%
Divorced Divorce, girlfriend/boyfriend	(2) 4% (1) 2%
Race and Ethnicity	
Black or African American	(18) 32%
Hispanic/Latino/Mexican American	(16) 28%
White	(16) 28%
African Latino and White	(3) 5% (4) 7%
Caregiver	
Yes	(52) 91%
No	(5) 9%
If Yes, Caregiver of:	
Biological children	(42) 82%
Relative	(7) 14%
Foster	(1) 2%
Adopt	(1) 2%

Care for child with special health care needs	
No	(31) 58%
Yes	(22) 42%
Language spoken most often	
English	(31) 61%
Spanish	(12) 24%
English and Spanish	(4) 8%
German and English; OR Arabic; OR English and Arabic; OR Nuba and Arabic	(1) 2% each
Place of Residence	
Urban	(30) 56%
Rural	(10) 18%
Suburban	(9) 17%
Border	(5) 9%
County	
Maricopa	(31) 54%
Cochise	(8) 14%
Santa Cruz	(8) 14%
Pima	(5) 9%
Yuma	(5) 9%
Birthplace	
Within the U.S., but not Arizona	(24) 45%
Country outside the U.S.	(19) 36%
Arizona	(10) 19%
Home	
Own house or condo	(31) 54%
Rent an apartment or house	(16) 28%
Trailer	(5) 9%
Live in someone else's home	(4) 7%
Rent an apartment and live with someone	(1) 2%
Employment	
Paid, full-time (40 hrs/wk)	(18) 32%
Paid, part-time (<40 hrs/wk)	(10) 18%
No paid work, not looking	(8) 14%
No paid work, looking for paid work Retired	(6) 11% (6) 11%
Paid, part-time and student	(2) 4%
Student; Part-time and have more than one job; Raise children; Dedicated to home; Political asylum; Full-time Volunteer	(1) 2% each

APPENDIX 5B: ADOLESCENT FOCUS GROUP DEMOGRAPHIC SURVEY RESULTS

Participants in focus groups were asked to complete a demographic survey. This table presents results from the surveys completed by adolescent participants.

Contextual Factors	N=54
Mean Age	16 years (S.D .1.6) Range: 14-23 years
Gender	
Female	(25) 46%
Male	(29) 54%
Non-binary, Two-spirit, Transgender (male to female), Transgender (female to male), Transgender nonconforming, Other	None Reported
Orientation	
Straight	(46) 85%
Lesbian or Gay	(2) 4%
Bisexual	(5) 9%
Pansexual	(1) 2%
Race and Ethnicity	
Hispanic/Latino/Mexican American	(31) 57%
White	(11) 20%
Latino and White	(5) 9%
Asian; American Indian and White	(2) 4% each
American Indian/Alaska Native and Latino; Asian and Latino	(1) 2% each
Caregiver	
Yes	(48) 89%
No	(6) 11%
If Yes, Caregiver of:	
Biological children	(5) 83%
Relative	(1) 17%
Foster; Adopt	None Reported
Place of Residence	
Rural	(30) 57%
Urban	(12) 23%
Border	(10) 19%
Suburban	(1) 2%
County	
Graham	(14) 26%
Gila	(12) 23%
Pinal	(8) 15%
Cochise; Santa Cruz	(7) 13% each
Pima	(5) 9%
Birthplace	
Arizona	(44) 83%
U.S., but not Arizona	(7) 13%
Mexico	(2) 4%

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