

# **Civil Rights and Disparities in Pediatric Healthcare Access for Racial and Ethnic Minority Families in Arizona**



A Report of the  
Arizona Advisory Committee to the  
U.S. Commission on Civil Rights

December 2024

## **Advisory Committees to the U.S. Commission on Civil Rights**

By law, the U.S. Commission on Civil Rights (Commission) has established an advisory committee in each of the 50 states, the District of Columbia, and the U.S. Territories. The committees are composed of state citizens who serve without compensation. The committees advise the Commission of civil rights issues in their states that are within the Commission's jurisdiction. More specifically, they are authorized to advise the Commission in writing of any knowledge or information they have of any alleged deprivation of voting rights and alleged discrimination based on race, color, religion, sex, age, disability, national origin, or in the administration of justice; advise the Commission on matters of their state's concern in the preparation of Commission reports to the President and the Congress; receive reports, suggestions, and recommendations from individuals, public officials, and representatives of public and private organizations to committee inquiries; forward advice and recommendations to the Commission, as requested; and observe any open hearing or conference conducted by the Commission in their states.



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## Letter of Transmittal to the U.S. Commission on Civil Rights

### Arizona Advisory Committee to the U.S. Commission on Civil Rights

The Arizona Advisory Committee to the U.S. Commission on Civil Rights submits this report examining the extent to which disparities exist in the access to and quality of pediatric healthcare for families who identify as a racial and/or ethnic minority in Arizona. The Committee submits this report as part of its responsibility to study and report on civil rights issues in the state of Arizona. The contents of this report are primarily based on testimony the Committee heard during web briefings on June 14, 2023; September 29, 2023; February 2, 2024; and March 26, 2024. It also includes written testimony submitted within the Committee's project timeline.

This report begins with a brief background of the issues to be considered by the Committee. It then presents primary findings as they emerged from this testimony, as well as recommendations for addressing areas of civil rights concerns. This report is intended to focus on civil rights concerns related to the extent to which, disparities exist in access to and quality of pediatric healthcare for Arizona families. While additional important topics may have surfaced throughout the Committee's inquiry, those matters that are outside the scope of this specific civil rights mandate are left for another discussion.

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## Project Overview

On January 6, 2023, the Arizona Advisory Committee (Committee) to the U.S. Commission on Civil Rights (Commission) adopted a proposal to study the extent to which disparities exist in the access to and quality of pediatric healthcare for families who identify as members of a racial and/or ethnic minority in Arizona. This report is intended to focus on civil rights concerns related to access to and quality of pediatric healthcare for Arizona families who identify as members of a racial and/or ethnic minority. As part of this inquiry, the Committee heard testimony via videoconference on June 14, 2023; September 29, 2023; February 2, 2024; and March 26, 2024. This report also includes written testimony submitted within the Committee's project timeline.<sup>1</sup>

The following report results from a review of testimony at these meetings along with written testimony<sup>2</sup> submitted to the Committee. It begins with a brief background of the issues considered by the Committee, followed by themes and findings as they emerged from this testimony. Finally, it makes recommendations for addressing related civil rights concerns. While other important topics may have surfaced during the Committee's inquiry, matters that are outside the scope of this specific civil rights mandate may be mentioned but are left for another discussion. This report and the recommendations included within it were adopted by a majority of Committee members present at a meeting on November 18, 2024.

## Purpose and Scope

The purpose of this report is to allow the Committee to advise the Commission regarding disparities, if any, in access to and quality of pediatric healthcare for families with children who identify as members of a racial and/or ethnic minority in Arizona. Notably, this study does not examine pre-natal healthcare. The Committee approached this study by limiting the scope to examining the following initial questions regarding access, factors, structure and design of the pediatric healthcare system, data collection, and recommendations for minimizing disparities across protected groups:

- (i) Are there racial and/or ethnic disparities in the provision and access of pediatric healthcare (ages birth to 18) in Arizona?

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<sup>1</sup> Meeting records and transcripts are available here: <https://usccr.box.com/s/dwf31qhnjgscvgydf9ctfbz1y89w6z3r>. Briefing before the *Arizona Advisory Committee to the U.S. Commission on Civil Rights*, June 14, 2023, (web-based), Transcript (hereafter cited as "6/14/23 Web Briefing"); Briefing before the *Arizona Advisory Committee to the U.S. Commission on Civil Rights*, September 29, 2023, (web-based), Transcript (hereafter cited as "9/29/23 Web Briefing"); Briefing before the *Arizona Advisory Committee to the U.S. Commission on Civil Rights*, February 2, 2024, (web-based), Transcript (hereafter cited as "2/2/24 Web Briefing"); Briefing before the *Arizona Advisory Committee to the U.S. Commission on Civil Rights*, March 26, 2024, (web-based), Transcript (hereafter cited as "3/26/24 Web Briefing").

<sup>2</sup> See <https://usccr.box.com/s/dwf31qhnjgscvgydf9ctfbz1y89w6z3r> for a folder containing written testimonies.

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- a. If so, what areas of pediatric healthcare do these disparities exist?
  - b. Are these disparities more prevalent with respect to particular groups (i.e., particular age or racial or ethnic groups)?
  - c. Are these disparities more prevalent in general pediatric healthcare providers or specialists?
- (ii) What are the potential causes or factors that contribute to these racial and/or ethnic disparities (e.g., location, financial barriers, racial and/or ethnic bias, etc.)?
    - a. Are the potential causes or factors related to these disparities attributable to providers? To the insurance industry? To historical racism/bias? To cultural differences?
    - b. Are there culture differences that may be affecting how pediatric healthcare is provided and/or how potential patients access treatment? Or preventing potential patients from even seeking treatment?
  - (iii) How might the current structure and design of the Arizona pediatric healthcare system contribute to these disparities?
  - (iv) Does the State of Arizona have sufficient data or systems to be able to sufficiently and accurately identify racial and/or ethnic disparities in pediatric healthcare?
    - a. What other kinds of data would researchers need to identify racial and/or ethnic disparities in pediatric healthcare?
  - (v) Are there other states where similar racial and/or ethnic disparities in pediatric healthcare do not exist?
    - a. If so, what potential reasons are there for the absence of racial and/or ethnic disparities in pediatric healthcare in those other states?
    - b. Are there new, existing, or targeted policies, government intervention, laws, or systems in other states that are successful in addressing the disparities seen in Arizona?
  - (vi) What laws, systems or programs have been implemented by the State of Arizona to address racial and/or ethnic disparities in pediatric healthcare, if any?
    - a. How successful have these been at minimizing or eliminating the disparities?
  - (vii) What can be done to minimize or eliminate these racial and/or ethnic disparities in pediatric healthcare in Arizona?

## Method

As a matter of historical precedent, and to achieve transparency, Committee studies involve a collection of public, testimonial evidence, and written comments from individuals directly affected by the civil rights topic at hand; researchers and experts who have rigorously studied and reported on the topic; community organizations and advocates representing a broad range of backgrounds

and perspectives related to the topic; and government officials tasked with related policy decisions and the administration of those policies.

Committee studies require Committee members to use their expertise in selecting a sample of panelists that is the most useful to the purposes of the study and will result in a broad understanding of the issue. This method of (non-probability) judgment sampling requires Committee members to draw from their own experiences, knowledge, opinions, and views to gain understanding of the issue and possible policy solutions. Committees are composed of volunteer professionals who are familiar with civil rights issues in their state or territory. Members represent a variety of political viewpoints, occupations, races, ages, and gender identities, as well as a variety of backgrounds, skills, and experiences. The intentional diversity of each Committee promotes vigorous debate and full exploration of the issues. It also assists in offsetting biases that can result in oversight of nuances in the testimony.

In fulfillment of Committees' responsibility to advise the Commission of civil rights matters in their locales, Committees conduct an in-depth review and thematic analysis of the testimony received and other data gathered throughout the course of their inquiry. Committee members use this publicly collected information, often from those directly affected by the civil rights topic of study, or others with direct expert knowledge of such matters, to identify findings and recommendations to report to the Commission. Drafts of the Committee's report are publicly available and shared with panelists and other contributors to ensure that their testimony was accurately captured. Reports are also shared with affected agencies to request clarification regarding allegations noted in testimony.

## **Background**

The Committee sought to examine the extent to which disparities exist in access to and quality of pediatric healthcare for racial and/or ethnic communities in Arizona. To approach the topic of disparities in pediatric healthcare—as a non-medicolegal federal advisory committee—the Committee felt it must develop a baseline understanding of the following topics: 1) available data and reporting 2) various factors that may explain racial and ethnic disparities, and 3) federal and state legislation related to pediatric healthcare. This report is based on both testimonies received at public web briefings and publicly available sources.

## **Focus on Access to and Quality of Pediatric Healthcare and Racial and Ethnic Communities in Arizona**

Disparities in access to and quality of healthcare is an enormous topic to tackle in the context of civil rights. In fact, the U.S. Commission on Civil Rights reported on this issue—first in 2010 as



a general topic,<sup>3</sup> and subsequently in relation to specific protected groups such as minority women and maternal healthcare.<sup>4</sup> The Commission has also reported twice on the topic of healthcare access for Native Americans.<sup>5</sup> In 2018, the Commission found that

The efforts of the federal government have been insufficient to meet the promises of providing for the health and wellbeing of tribal citizens, as a vast health disparity exists today between Native Americans and other population groups.<sup>6</sup>

Various advisory committees also have examined this topic to some degree, especially in the wake of the COVID-19 pandemic.<sup>7</sup>

The Arizona Advisory Committee decided to narrow its focus to address disparities in access to and quality of pediatric healthcare affecting families who identify as members of racial and/or ethnic minority groups. This approach allowed the Committee to better utilize publicly available data as a foundation for its inquiry. By examining only “pediatric healthcare,” the Committee restricted its analysis to information relevant to children aged 0 (post-natal) to 18 years. In addition, the Committee focused specifically on traditional physical medicine—excluding dental, vision, and mental health services—with the project centering on medical services provided primarily by pediatric physicians (M.D.s) throughout Arizona.

The Committee also examined disparities based on the race and/or ethnicity of the child patient, rather than that of the parent or legal guardian. Although the Committee was interested in

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<sup>3</sup> U.S. Commission on Civil Rights, *Health Care Disparities*, Dec. 2010, <https://www.usccr.gov/files/pubs/docs/Healthcare-Disparities.pdf>; U.S. Commission on Civil Rights, *Funding Federal Civil Rights Enforcement: 2000 and Beyond*, Apr. 2002, <https://www.usccr.gov/files/pubs/archives/crfund02/report.pdf>; U.S. Commission on Civil Rights, *The Health Care Challenge: Acknowledging Disparity, Confronting Discrimination, and Ensuring Equality, Vols. I and II.*, Sept. 1999, <https://www2.law.umaryland.edu/marshall/usccr/documents/cr12h34z.pdf>.

<sup>4</sup> U.S. Commission on Civil Rights, *Racial Disparities in Maternal Health*, Sept. 2021, <https://www.usccr.gov/files/2021/09-15-Racial-Disparities-in-Maternal-Health.pdf>.

<sup>5</sup> U.S. Commission on Civil Rights, *Native American Health Care Disparities Briefing*, Feb. 2004, <https://www2.law.umaryland.edu/marshall/usccr/documents/nativeamericanhealthcaredis.pdf>; U.S. Commission on Civil Rights, *Broken Promises: Continuing Federal Funding Shortfall for Native Americans*, Dec. 2018, <https://www.usccr.gov/files/pubs/2018/12-20-Broken-Promises.pdf>.

<sup>6</sup> U.S. Commission on Civil Rights, *Broken Promises: Continuing Federal Funding Shortfall for Native Americans*, Dec. 2018, p. 65, <https://www.usccr.gov/files/pubs/2018/12-20-Broken-Promises.pdf>.

<sup>7</sup> Hawai‘i Advisory Committee to the U.S. Commission on Civil Rights, *COVID-19 and Pacific Islander Communities in Hawai‘i*, May 2021, <https://www.usccr.gov/reports/2021/covid-19-and-pacific-islander-communities-hawaii>; Maryland Advisory Committee to the U.S. Commission on Civil Rights, *COVID-19 and Health Disparities in Maryland*, Feb. 2021, <https://www.usccr.gov/files/2021/04-20-MD-SAC-COVID-19-and-Health-Disparities-Advisory-Memo.pdf>; Ohio Advisory Committee to the U.S. Commission on Civil Rights, *Civil Rights and Equity in the Delivery of Medical and Public Services During the COVID-19 Pandemic in Ohio*, Nov. 2020, <https://www.usccr.gov/files/2021/02-08-OH-COVID-Health-Disparities.pdf>.

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examining a child patient’s access to healthcare, it recognized that a child’s dependency on a parent or guardian for financing, scheduling, and receiving healthcare is an important factor that affects a child’s access to healthcare. Furthermore, the Committee focused on examining the extent to which racial/ethnic disparities exist in the delivery of care—such as access to healthcare and quality of care— rather than disparities in health outcomes or health status.

Arizona is home to 22 federally recognized Native American tribes, with significant populations on tribal reservations. The largest reservations include the Navajo Nation, which extends into Utah and New Mexico, and the Tohono O’odham Nation in the southern part of the state. Most of Arizona’s population live in urban areas, with the Phoenix metropolitan area alone housing about 4.7 million people. A smaller portion of the population lives in rural areas, which include vast tracts of land and numerous small towns and tribal reservations.

Studying this topic is timely as Arizona is one of the fastest growing and most diverse states in the U.S. making it eighth in the nation for overall population growth from 2010 to 2019 (13.9 percent growth), and second in the nation for growth in 2020 alone (1.78 percent). Growth is expected to continue by an additional 30 percent by 2055. Arizona is home to approximately 7.4 million residents, with both the fifth largest city and the fifth largest portion of frontier area in the nation, a 389-mile international border with Mexico, and twenty-two sovereign Native American communities. Forty-six percent of its residents identify as a part of a minority racial or ethnic group.<sup>8</sup>

## Topic Overview

National and state-specific data regarding access to and quality of pediatric healthcare is fragmented and challenge to obtain—it is also not disaggregated further by subpopulations. Despite the difficulty in analyzing data, the Advisory Committee heard from several witnesses who experienced disparities in access to, and quality of, healthcare for racial and/or ethnic minorities. To the extent that disparities in access and quality of care exist, it affects health outcomes within these communities.

Citing research published between 1950 and 2007 on racial/ethnic<sup>9</sup> disparities in children’s health

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<sup>8</sup> Arizona Department of Health Services, Bureau of Women’s and Children’s Health, *Arizona Primary Care Needs Assessment*, Mar. 2021, <https://www.azdhs.gov/documents/prevention/health-systems-development/data-reports-maps/reports/primary-care-needs-assessment-final.pdf> (hereafter cited as Arizona Department of Health Services, *2021 Arizona Primary Care Needs Assessment*).

<sup>9</sup> To clarify the difference, all racial categories can include persons of Hispanic and non-Hispanic origin. Ethnic categories are: Hispanic or Latino, non-Hispanic White, and non-Hispanic African American. Hispanics can be of any race.

and healthcare,<sup>10</sup> Dr. Glen Flores, of the American Academy of Pediatrics found that racial and ethnic disparities in children’s health and pediatric healthcare are “extensive, pervasive, and persistent.”<sup>11</sup> Dr. Flores’s 2010 study revealed disparities spanned across an array of health and healthcare related matters, including—but not limited to—mortality rates and chronic diseases, access to care and use of services, prevention and population health, health status, special healthcare needs, and quality of care.<sup>12</sup> Similarly, in a 2024 meta-study, researchers examined studies focused on racial and ethnic inequities in the quality of pediatric care and found widespread patterns of inequitable treatment across pediatric specialties including neonatology, primary care, emergency medicine, inpatient and critical care, surgery, developmental disabilities, mental healthcare, endocrinology, and palliative care. The identified studies indicate that children from racial and ethnic minority groups received poorer healthcare services relative to non-Hispanic White children, with most studies drawing on data from multiple sites, and accounting for indicators of family socioeconomic position and clinical characteristics (e.g. comorbidities or condition severity).<sup>13</sup>

What is notable among research examining disparities in access to healthcare is the identification of racism as a factor. For instance, a 2020 article in *Nursing Administration Quarterly* stated:

Generational harm done to the Black community has eroded trust in the healthcare system. Racial biases, largely unconscious, held by healthcare professionals can directly result in morbidity and mortality.<sup>14</sup>

Similar findings have spurred the American Academy of Pediatrics to release a policy statement

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<sup>10</sup> Glenn Flores, The Committee on Pediatric Research; Racial and Ethnic Disparities in the Health and Health Care of Children. *Pediatrics* April 2010; 125 (4): e979–e1020. 10.1542/peds.2010-0188 <https://publications.aap.org/pediatrics/article/125/4/e979/73118/Racial-and-Ethnic-Disparities-in-the-Health-and?autologincheck=redirected> (hereafter cited as Flores, *Racial and Ethnic Disparities in the Health and Health Care of Children*).

<sup>11</sup> *Ibid.*

<sup>12</sup> *Ibid.* Note that of the 109 articles that the Flores Report reviewed, 94 of 109 addressed disparities in African American children; 66 of 109 articles addressed disparities in Latino children; 24 of 109 articles addressed disparities in Asian/Pacific Islander children; and, 16 of 109 articles addressed disparities in American Indian/Alaska Natives children.

<sup>13</sup> Slopen, Natalie, Andrew R Chang, Tiffani J Johnson, Ashaunta T Anderson, Aleha M Bate, Shawnese Clark, Alyssa Cohen, et al. “Racial and Ethnic Inequities in the Quality of Paediatric Care in the USA: A Review of Quantitative Evidence.” *The Lancet. Child & Adolescent Health* 8, no. 2 (February 1, 2024): 147–58. [https://doi.org/10.1016/s2352-4642\(23\)00251-1](https://doi.org/10.1016/s2352-4642(23)00251-1).

<sup>14</sup> Laura Watson and Mia Malcolm, “Racism as a Preventable Harm,” *Nursing Administration Quarterly*, vol. 45, no. 4 (2020), pp. 302-10.

highlighting the role of racism in child and adolescent development and health outcomes.<sup>15</sup> In their 2019 statement, they provide evidence-based research focused those concerns and conclude: “racism is a social determinant of health that has a profound impact on the health status of children, adolescents, emerging adults, and their families.”<sup>16</sup>

### Available National Data

National data that highlight healthcare quality and disparities can be found in the National Healthcare Disparities Report (NHDR);<sup>17</sup> however, data on children’s access to healthcare is somewhat limited.<sup>18</sup> Traditional measures of mainstream healthcare—such as care provided in physicians’ offices, hospitals, and emergency departments—are not necessarily reflective of children’s healthcare needs accurately. Additionally, children sometimes do not have a usual source of care<sup>19</sup> and instead receive health services outside of the mainstream healthcare system, such as schools, public specialty clinics, and from non-physician subspecialists.<sup>20</sup> Having a usual source of care is an essential factor for access to healthcare for children. Yet, many children still

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<sup>15</sup> Maria Trent, Danielle G. Dooley, Jacqueline Dougé, Section on Adolescent Health, Council On Community Pediatrics, Committee On Adolescence, Robert M. Cavanaugh, Amy E. Lacroix, Jonathon Fanburg, Maria H. Rahmandar, Laurie L. Hornberger, Marcie B. Schneider, Sophia Yen, Lance Alix Chilton, Andrea E. Green, Kimberley Jo Dille, Juan Raul Gutierrez, James H. Duffee, Virginia A. Keane, Scott Daniel Krugman, Carla Dawn McKelvey, Julie Michelle Linton, Jacqueline Lee Nelson, Gerri Mattson, Cora C. Breuner, Elizabeth M. Alderman, Laura K. Grubb, Janet Lee, Makia E. Powers, Maria H. Rahmandar, Krishna K. Upadhy, Stephenie B. Wallace; The Impact of Racism on Child and Adolescent Health. *Pediatrics* August 2019; 144 (2): e20191765. 10.1542/peds.2019-1765. (hereafter cited as, American Academy of Pediatrics, *The Impact of Racism on Child and Adolescent Health*).

<sup>16</sup> Berman G, Paradies Y. Racism, disadvantage and multiculturalism: towards effective anti-racist praxis. *Ethn Racial Stud.* 2010;33(2):214–232; Elias A, Paradies Y. Estimating the mental health costs of racial discrimination. *BMC Public Health.* 2016;16(1):1205; Heard-Garris NJ, Cale M, Camaj L, Hamati MC, Dominguez TP. Transmitting Trauma: a systematic review of vicarious racism and child health. *Soc Sci Med.* 2018;199:230–240; Pachter LM, Coll CG. Racism and child health: a review of the literature and future directions. *J Dev Behav Pediatr.* 2009;30(3):255–263; Paradies Y. Defining, conceptualizing and characterizing racism in health research. *Crit Public Health.* 2006; 16(2):144–157; Pachter LM, Bernstein BA, Szalacha LA, Garcia Coll C. Perceived racism and discrimination in children and youths: an exploratory study. *Health Soc Work.* 2010;35(1):61–69

<sup>17</sup> U.S. Department of Health and Human Services, Agency for Healthcare Research and Quality, National Healthcare Disparities Reports, <https://www.ahrq.gov/research/findings/nhqrdr/index.html>.

<sup>18</sup> In 2003, the U.S. Department of Health and Human Services Agency for Healthcare Research and Quality conducted its first annual report on healthcare disparities.

<sup>19</sup> “Usual Source of Care” can be defined as a particular doctor’s office, clinic, health center, or other place to go for medical care when ill or for health-related advice.

<sup>20</sup> U.S. Department of Health and Human Services, Agency for Healthcare Research and Quality, National Healthcare Disparities Reports, <https://www.ahrq.gov/research/findings/nhqrdr/index.html>.

lack this resource.<sup>21</sup> Without a usual source of care, children may not receive the appropriate level of recommended medical care, such as routine wellness exams and immunizations.

In 2014, approximately 7.9 percent of all children under eighteen (about 5.8 million children) across the nation reported that they did not have a usual source of care.<sup>22</sup> As estimate of 10.4 percent of Hispanic children and 10.3 percent of Black children were more likely to lack a usual source of care in comparison to 5.9 percent of White children.<sup>23</sup> In a separate report, Native American/Alaska Native children are three times as likely as their White counterparts to lack coverage (11.9 percent vs. 3.9 percent).<sup>24</sup>

The NHDR also confirms that racial and ethnic minorities are less likely to have a usual source of care.<sup>25</sup> For example, 49 percent of Native American/Alaska Natives and 28 percent of Black identify a hospital, clinic, or emergency department as their usual source of care rather than a primary care physician.<sup>26</sup>

Insurance status is also a key factor in a child's ability to access healthcare. In 2014, uninsured children were more than five times likely to lack a usual source of care as children with private insurance.<sup>27</sup> By 2021, 53.1 percent of children aged 0-17 had private health insurance while 44.7 percent of children had public coverage; 4.4 percent remained uninsured.<sup>28</sup>

Scheduling an appointment also presents another barrier to accessing healthcare. According to the NHDR, Black, Native American/Alaska Natives, and Hispanic children report more difficulty

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<sup>21</sup> Zewde, N., Berdahl, T. *Children's Usual Source of Care: Insurance, Income, and Racial/Ethnic Disparities*, 2014. Statistical Brief #501. March 2017. Agency for Healthcare Research and Quality, Rockville, MD. [http://meps.ahrq.gov/mepsweb/data\\_files/publications/st501/stat501.pdf](http://meps.ahrq.gov/mepsweb/data_files/publications/st501/stat501.pdf), (hereafter cited as Agency for Healthcare Research and Quality, *2014 Children's Usual Source of Care: Insurance, Income, and Racial/Ethnic Disparities*).

<sup>22</sup> Ibid.

<sup>23</sup> Ibid.

<sup>24</sup> Latoya Hill, Samantha Artiga, and Anthony Damico, "Health Coverage by Race and Ethnicity, 2010-2022", KFF, Jan. 11, 2024, <https://www.kff.org/racial-equity-and-health-policy/issue-brief/health-coverage-by-race-and-ethnicity/>.

<sup>25</sup> U.S. Department of Health and Human Services, Agency for Healthcare Research and Quality, *National Healthcare Disparities Report*, Jul. 2003, <https://repository.library.georgetown.edu/bitstream/handle/10822/711771/NHDR2003.pdf?sequence=1>, (hereafter cited as Agency for Healthcare Research and Quality, *NHDR Report 2003*).

<sup>26</sup> Ibid.

<sup>27</sup> Agency for Healthcare Research and Quality, *2014 Children's Usual Source of Care: Insurance, Income, and Racial/Ethnic Disparities*, p. 3. (Specifically, about 31.4 percent of uninsured children reported lacking a usual source of care in comparison to 6.2 percent of privately insured children).

<sup>28</sup> 2021 National Healthcare Quality and Disparities Report. Rockville, MD: Agency for Healthcare Research and Quality; December 2021. AHRQ Pub. No. 21(22)-0054-EF, p. A-16 <https://www.ahrq.gov/sites/default/files/wysiwyg/research/findings/nhqrdr/2021qdr.pdf> (hereafter cited as Agency for Healthcare Research and Quality, *NHDR Report 2021*).

scheduling appointments in off-peak hours (i.e., outside of normal working hours) compared to White and non-Hispanic children.<sup>29</sup> Specifically, in 2017, Hispanic children were more likely than non-Hispanic White children to sometimes or never get an appointment for routine care as soon as needed.<sup>30</sup> Also, Asian and Black children were more likely than White children to sometimes or never get an appointment for routine care as soon as needed.<sup>31</sup> Once at the doctor's office, Black and Hispanic children are more likely to wait more than 30 minutes to see their usual source of care, which is longer than wait times for non-Hispanic White children.<sup>32</sup> Furthermore, Black children are more likely than White children to have an hour or more wait for semi-urgent or non-urgent emergency department care.<sup>33</sup>

“Quality healthcare” can be defined as “doing the right thing at the right time in the right way for the right person and having the best results possible.”<sup>34</sup> While numerous healthcare quality exist, their collective ability to comprehensively assess children's healthcare is unclear.

There are several instruments designed to measure the quality of healthcare for children. However, Beal, et al., note that there are

relatively few measures for assessing patient safety and living with illness and none for end-of-life care. Few measures are designed for specific age categories among children. Although equity is an overarching concern in healthcare quality, the application of current measures to assess disparities has been limited. These areas need additional research and development for a more complete assessment of healthcare quality for children.<sup>35</sup>

The NHDR analyzed the effectiveness of care for children and found that there is limited evidence on whether specific child healthcare interventions are effective.<sup>36</sup> However, research has identified

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<sup>29</sup> Agency for Healthcare Research and Quality, *NHDR Report 2003*, pp. 168-9.

<sup>30</sup> Agency for Healthcare Research and Quality, *NHDR Report 2021*, p. A-28 (Noting that 6.6 percent of Hispanic children reported sometimes or never getting an appointment vs. 4.5 percent of non-Hispanic White children.).

<sup>31</sup> Agency for Healthcare Research and Quality, *NHDR Report 2021*, p. A-28 (Noting 11.4 percent of Asian children and 8.7 percent of African American children reported sometimes or never getting an appointment vs. 4.9 percent of White children.).

<sup>32</sup> Agency for Healthcare Research and Quality, *NHDR Report 2003*, p. 122 (Noting 19 percent of African American children vs. 15 percent of White children, 25 percent of Hispanic children vs. 13 percent of non-Hispanic White children, and 26 percent of “poor” children vs. 10 percent of high-income children, report longer waiting times. *Ibid.*

<sup>33</sup> *Ibid.*, p. 169 (Noting 33 percent of African American children vs. 25 percent of White children reported having to wait an hour or more for semi-urgent or non-urgent ED care.).

<sup>34</sup> Agency for Healthcare Research and Quality, *NHDR Report 2021*, p. Q-1.

<sup>35</sup> Beal AC, Co JP, Dougherty D, Jorsling T, Kam J, Perrin J, Palmer RH. Quality measures for children's health care. *Pediatrics*. 2004 Jan;113(1 Pt 2):199-209. PMID: 14702502.

<sup>36</sup> Agency for Healthcare Research and Quality, *NHDR Report 2003*, p. 163.

disparities in the quality of care including HIV/AIDS,<sup>37</sup> childhood obesity,<sup>38</sup> childhood and adolescent immunization,<sup>39</sup> and respiratory diseases.<sup>40</sup>

Several disparities in quality of care have been specifically identified for Black children. For example, Black children with end-stage renal disease were substantially less likely than White children to be activated on the kidney transplant waiting list.<sup>41</sup> Additionally, Black children were less likely to receive preemptive kidney transplants and received fewer living transplants and more cadaveric transplants than White children.<sup>42</sup> In another example, Black children who were heart transplant patients had twice the odds of graft failure and lower graft survival rates compared to White children.<sup>43</sup> Also, the median graft survival time for Black children is about six years less than White children.<sup>44</sup>

Other disparities affect Black and Latino families, where parents often report that healthcare providers “never or only sometimes understood the child’s specific needs and how the parent prefers to rear the child.”<sup>45</sup> These perceptions, along with discussions that prioritize social concerns such as community violence or household substance use, may discourage parents from

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<sup>37</sup> Ibid., Agency for Healthcare Research and Quality, *NHDR Report 2003*, p. D-44. (Noting the CDC HIV/AIDS Surveillance System, new AIDS cases are being reported at a higher rate among non-Hispanic African American and Hispanic adolescents (13 to 17 years) compared with non-Hispanic White adolescents. Additionally, there are higher rates of HIV infection among African American children compared to White children.)

<sup>38</sup> Agency for Healthcare Research and Quality, *NHDR Report 2021*.

<sup>39</sup> Agency for Healthcare Research and Quality, *NHDR Report 2003*, p. 59. (Regarding childhood immunizations, the NHDR also found that African American children are less likely to receive them compared to White children, and lower-income children are less likely to receive immunizations compared to “high-income” children.)

<sup>40</sup> Ibid., p. 64. (The NHDR found that, in relation to the treatment of upper respiratory infections, hospitalization rates among African American children tend to be higher than rates among White children.)

<sup>41</sup> Furth SL, Garg PP, Neu AM, Hwang W, Fivush BA, Powe NR. Racial differences in access to the kidney transplant waiting list for children and adolescents with end-stage renal disease. *Pediatrics*. 2000; 106(4): 756–761, According to the Organ Donation Alliance, an active candidate is defined as, “a transplant candidate eligible to be considered for organ offers at a given point in time. Some transplant candidates are temporarily classified as “inactive” by their transplant center because they are medically unsuitable for transplantation or need to complete other eligibility requirements.” (OPTN Glossary May 2021) <https://www.organdonationalliance.org/glossary/active-candidate/>.

<sup>42</sup> Omoloja A, Stolfi A, Mitsnefes M. Racial differences in pediatric renal transplantation: 24-year single center experience. *J Natl Med Assoc*. 2006; 98(2): 154–157.

<sup>43</sup> Mahle WT, Kanter KR, Vincent RN. Disparities in outcome for black patients after pediatric heart transplantation. *J Pediatr*. 2005; 147(6): 739–743.

<sup>44</sup> Ibid.

<sup>45</sup> Flores G, Olson L, Tomany-Korman SC. Racial and ethnic disparities in early childhood health and health care. *Pediatrics*. 2005, 115(2), [www.pediatrics.org/cgi/content/full/115/2/e183](http://www.pediatrics.org/cgi/content/full/115/2/e183).

seeking care.<sup>46</sup>

Language barriers between patients/patients' parents and healthcare providers can also impact the quality of care.<sup>47</sup> For example, Asian/Pacific Islander parents who primarily speak a language other than English reported lower primary care quality scores across multiple areas compared to English-speaking counterparts.<sup>48</sup>

### *Federal Legislation Related to Pediatric Healthcare*

There are several laws related to pediatric healthcare access and quality. Below include those that are largely applicable.

Title VI of the Civil Rights Act of 1964 protects persons against discrimination based on race, color, or national origin in programs and activities that receive Federal financial assistance.<sup>49</sup> Persons eligible for public assistance, Medicaid, or other social services cannot be denied assistance because of race, color, or national origin.

The Indian Healthcare Improvement Act (IHCIA)<sup>50</sup> is a cornerstone legal authority for the provision of healthcare to Native American and Alaska Natives and was made permanent by the Affordable Care Act.<sup>51</sup> The IHCIA's primary purpose is to provide comprehensive healthcare services to Native Americans and Alaska Natives through the IHS. It addresses the severe health disparities experienced by these populations and aims to improve their overall health status. In the context of pediatric healthcare, IHCIA ensures that Native American and Alaska Native children have access to a full range of healthcare services. This includes routine pediatric care, immunizations, well-child visits, and specialized medical services.

Two years after the Social Security Amendments of 1965,<sup>52</sup> the Medicaid benefit for children and adolescents up to age 21, known as Early and Periodic Screening, Diagnostic and Treatment

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<sup>46</sup> Molina Testimony, *3/26/24 Web Briefing*, pp. 14-5; Haskon Testimony, *3/26/24 Web Briefing*, p. 12; Lovell Testimony, *3/26/24 Web Briefing*, pp. 9-10.

<sup>47</sup> Weech-Maldonado R, Morales LS, Spritzer K, Elliott M, Hays RD. Racial and ethnic differences in parents' assessments of pediatric care in Medicaid managed care. *Health Serv Res.* 2001; 36(3): 575–594.

<sup>48</sup> Ibid.

<sup>49</sup> 42 U.S.C. § 2000d.

<sup>50</sup> 25 U.S.C. § Ch. 18.

<sup>51</sup> Patient Protection and Affordable Care Act, Pub. L. No. 111-148, 124 Stat. 119 (2010); Congressional Research Service, *The Indian Health Care Improvement Act Reauthorization and Extension as Enacted by the ACA: Detailed Summary and Timeline*, January 3, 2014, <https://crsreports.congress.gov/product/pdf/R/R41630>.

<sup>52</sup> Pub. L. No. 89-97, 79 Stat. 286.



(EPSDT), was enacted as a mandated service.<sup>53</sup> The goal of this benefit is to ensure that children under the age of 21 who are enrolled in Medicaid receive age-appropriate screening, preventive services, and treatment services that are medically necessary to correct or ameliorate any identified conditions.<sup>54</sup>

Additionally, the Balanced Budget Act of 1997,<sup>55</sup> the Children’s Health Insurance Program (CHIP) expanded Medicaid to provide insurance coverage to uninsured, low-income children above Medicaid income eligibility thresholds.<sup>56</sup> States may use CHIP funds to create a separate CHIP program, expand their Medicaid program, or adopt a combination approach.<sup>57</sup>

### **Disparities in Access to Pediatric Healthcare in Arizona**

National data on pediatric healthcare disparities is limited, and accessing Arizona-specific data is particularly challenging.<sup>58</sup> While comprehensive data systems exist, they are difficult to obtain and frequently lack disaggregation by race, ethnicity, income, or geography.<sup>59</sup> Significant data gaps exist, especially for rural and Native American populations. The siloed nature of data systems, particularly those of Indian Health Services (IHS) and 638 tribal healthcare facilities, further complicates access. Effective collaboration with tribal communities is essential for obtaining accurate data and addressing healthcare disparities more effectively.<sup>60</sup>

Arizona has one of the highest levels of uninsured children in the United States. As of 2022, approximately 142,000 children under the age of 19 in Arizona lacked health insurance, representing 8.4 percent of the population. This rate is higher than the national average of 5.1 percent and ranks fifth highest in the country, following Texas, Florida, California and Georgia. This raises concerns about healthcare access among the various racial and ethnic communities,

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<sup>53</sup> 42 U.S.C. § 1396d(r).

<sup>54</sup> Centers for Medicare & Medicaid Services, “Early and Periodic Screening, Diagnostic, and Treatment | Medicaid,” n.d., <https://www.medicaid.gov/medicaid/benefits/early-and-periodic-screening-diagnostic-and-treatment/index.html>.

<sup>55</sup> Pub. L. No. 105-33, 111 Stat 251.

<sup>56</sup> 42 U.S.C. § 1397aa *et seq.*

<sup>57</sup> *Id.*

<sup>58</sup> Children’s Action Alliance, “2020 Arizona Kids Count Data Book,” 2020, <https://azchildren.org/wp-content/uploads/2020/10/2020-KIDS-COUNT-Data-Book.pdf>.

<sup>59</sup> Navajo Native American Research Centers for Health (NARCH) Partnership between Diné College and Northern Arizona University, Navajo Nation Department of Health, and Arizona Department of Health. 2020 Navajo Nation Maternal and Child Health Needs Assessment. 2020. The report states that 76 percent of children between 3-27 months old received the appropriate immunizations. The report indicates, however, that the data only includes 6 of 12 Indian Health Care Facilities.

<sup>60</sup> Haskon Testimony, 3/26/24 *Web Briefing*, pp. 12-3.

where a majority of Arizona's population identifies as non-White.

### *Access to Pediatric Healthcare in Arizona*

Access to healthcare and maintaining healthcare coverage continues to be a significant problem for minority children and families with minority children in Arizona. Latino families are less likely to have access to affordable employer-sponsored health insurance and are disproportionately enrolled in Arizona's Medicaid and CHIP programs. Meanwhile, approximately 18.4 percent of Native American children in Arizona lack health insurance, more than double the rate for all children in the state (8.4 percent). Apache County, home to the state's largest concentration of Native American children, has the highest percentage of uninsured children at 22 percent.

Rural communities also face substantial challenges in accessing healthcare, particularly outside the Phoenix metropolitan area. The state's population is spread across expansive rural and frontier landscapes, resulting in a low population density of just 56.3 people per square mile, well below the national average of 87.4. Factors such as long travel distances, unpaved roads, and occasional border patrol checkpoints create barriers to care, especially for the majority-rural populations residing on tribal reservations. For instance, children with conditions such as juvenile arthritis may need to travel up to 246 miles to access specialized care in Arizona.<sup>61</sup>

One of the most notable concerns about access to pediatric healthcare in Arizona arose in January 2010 when the state froze enrollment in KidsCare just weeks before Congress passed the Affordable Care Act (ACA) with a "maintenance of effort" (MOE) provision.<sup>62</sup> That provision protected children's Medicaid and CHIP eligibility and enrollment across all other states.<sup>63</sup> At that time, Arizona was the only state with such a freeze in place.<sup>64</sup> To address this gap for Arizona families until new coverage options became available under the ACA, the state and federal government developed a creative hospital financing agreement that would reopen enrollment under KidsCare II in May 2012.<sup>65</sup> At the end of 2009, Arizona stopped enrolling new applicants for coverage effective January 1, 2010. More than 120,00 children were on waiting lists in the event

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<sup>61</sup> American Academy of Pediatrics, "Pediatric Subspecialty Shortages: A Threat to Children's Health," [https://downloads.aap.org/AAP/PDF/Advocacy/Arizona\\_SubspecialtyFactSheet.pdf](https://downloads.aap.org/AAP/PDF/Advocacy/Arizona_SubspecialtyFactSheet.pdf).

<sup>62</sup> Patient Protection and Affordable Care Act, Pub. L. No. 111-148, 124 Stat. 119 (2010).

<sup>63</sup> *Id.*; The Affordable Care Act includes a "maintenance of effort" provision, requiring states to maintain current Medicaid eligibility and enrollment policies as of March 23, 2010, for adults until January 2014 and for children through September 2019.

<sup>64</sup> "The Arizona KidsCare CHIP Enrollment Freeze: How Has It Impacted Enrollment and Families?," The Kaiser Commission on Medicaid and the Uninsured, 2011, p. 1, <https://www.kff.org/wp-content/uploads/2013/01/8232.pdf> (hereafter cited as The Kaiser Commission on Medicaid and the Uninsured, *The Arizona KidsCare CHIP Enrollment Freeze*.)

<sup>65</sup> Tricia Brooks et al., Georgetown Center for Children and Families, "Dismantling CHIP in Arizona: How Losing KidsCare Impacts a Child's Health Care Costs," May 2014, pp. 4-5, <https://ccf.georgetown.edu/wp-content/uploads/2014/05/Dismantling-CHIP-in-Arizona.pdf>.

that KidsCare was reinstated. In May 2012, KidsCare II opened enrollment and the state began accepting new applications, prioritizing children on the wait list with income below 175 percent federal poverty level. At the peak of enrollment, this program served 47,000 children. Despite that effort, Arizona's ranking in children's health coverage fell from 47th to 49th, with only Alaska and Nevada having higher rates of uninsured children.<sup>66</sup> While the CHIP enrollment freeze saved Arizona \$12.9 million in FY 2011, it also resulted in over 100,000 children being placed on a waiting list for coverage and the loss of \$41 million in federal matching funds.<sup>67</sup>

Fast forward to 2024: Arizona has attempted to increase access to healthcare is now 1 of 38 states offering a CHIP Medicaid expansion program, as well as a separate CHIP ("KidsCare").<sup>68</sup> In 2023, Arizona enacted a change to its Medicaid qualifications and expanded its parameters for children to get Medicaid coverage; this has the potential to give healthcare coverage to 10,000 more kids beginning April 1, 2024.<sup>69</sup> To qualify for the program, the annual family income limit is 225 percent of the federal poverty level. The state is seeking approval from the Centers for Medicaid and Medicare Services and applied for a Section 1115 waiver<sup>70</sup> to expand its Medicaid coverage for five years. If approved, Arizona Health Care Cost Containment System (AHCCCS) officials say Arizona will become the first state in the nation to expand CHIP financial eligibility.<sup>71</sup>

According to the most recent CHIP Annual Report for Arizona (FY 2021), 76,269 children were enrolled in the CHIP Medicaid Expansion Program and 57,859 children were enrolled in the Separate Child Health Insurance Program.<sup>72</sup> Due to the effects of the COVID-19 pandemic, the most recent data for uninsurance rates were not reported to the Centers for Medicare & Medicaid.<sup>73</sup>

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<sup>66</sup> Georgetown Center for Children and Families analysis of uninsured data for children from the Census Bureau's American Community Survey, 2008 – 2012, as reported in annual briefs on uninsured children.

<sup>67</sup> The Kaiser Commission on Medicaid and the Uninsured, *The Arizona KidsCare CHIP Enrollment Freeze*, p. 2.

<sup>68</sup> Centers for Medicare & Medicaid Services, "CHIP Program Structure by State," <https://www.medicaid.gov/chip/downloads/chip-map.pdf> (accessed on June 28, 2024).

<sup>69</sup> "AHCCCS News & Updates," n.d., <https://www.azahcccs.gov/shared/News/PressRelease/IncreasedAccessToChildHealthCare.html>.

<sup>70</sup> Social Security Amendment Act § 1115, 42 U.S.C. § 1315(a)(1); Section 1115 waivers offer states an avenue to test new approaches in Medicaid that differ from what is required by federal statute and can provide states considerable flexibility in how they operate their programs. Generally, these waivers are subject to approval by the Centers for Medicaid and Medicare Services for an initial five-year period and can be extended for up to an additional three to five years, depending on the populations served, <https://www.medicaid.gov/medicaid/section-1115-demonstrations/about-section-1115-demonstrations/index.html>.

<sup>71</sup> Arizona Health Care Cost Containment System, "Two Medicaid Program Changes Increase Access to Health Care for Children," Feb. 20, 2024, <https://www.azahcccs.gov/shared/News/PressRelease/IncreasedAccessToChildHealthCare.html>.

<sup>72</sup> Alex Demyan and Arizona Health Care Cost Containment System, "Arizona CARTS FY2021 Report," 2021, <https://www.medicaid.gov/CHIP/downloads/az-2021chipannualreport.pdf>.

<sup>73</sup> Ibid.

According to the University of Arizona's Center for Rural Health, the number of physicians specializing in pediatrics is disproportionately higher in urban areas compared to rural areas.<sup>74</sup> Out of 1,208 pediatricians located in Arizona, 1143 pediatricians (95 percent) provide care in urban areas compared to just 4 pediatricians (2 percent) who provide care in rural areas. Children living in rural areas of Arizona must travel farther distances to receive care compared to their urban counterparts.<sup>75</sup>

This challenge is particularly acute when children in rural areas of Arizona require access to subspecialty care. According to the American Academy of Pediatrics, 19.3 percent of children in Arizona require special healthcare services for conditions such as cancer, Down syndrome, asthma, and depression.<sup>76</sup> However, Arizona faces a scarcity of key pediatric subspecialists, with only 52 pediatric anesthesiologists, 47 pediatric cardiologists, 46 pediatric hematologists and oncologists, and 75 pediatric critical care physicians.<sup>77</sup> Notably, all 52 pediatric anesthesiologists and 47 pediatric cardiologists practice exclusively in urban areas, with the majority of pediatric hematologists and oncologists also located in urban settings.<sup>78</sup>

When looking at Arizona's health workforce profiles, there is a severe shortage/scarcity of critical care physicians and nurses in counties with smaller and medium-sized populations. For example, the two largest, most populous counties in Arizona (Maricopa and Pima Counties) maintain a little over 1,000 critical care physicians, compared to about 250 critical care physicians in less<sup>79</sup> and lesser<sup>80</sup> populated counties combined.<sup>81</sup> Some of the less populated counties have large tribal and/or minority populations. Apache County has one hospital, no Intensive Care Unit beds, and less than one-third the amount of critical care physicians and nurses per capita compared to all of Arizona. A shortage of doctors or hospitals in proximity may be a key barrier to obtaining adequate healthcare.

The proximity of healthcare providers is likely linked to the whether a child will establish a usual

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<sup>74</sup> Koch B, Coates S, Drake C, and Derksen D. (2022) Arizona Health Workforce Profile: Physician Specialty.

<sup>75</sup> National Organization of Association of State and State Offices of Rural Health Territorial and Association of State and Territorial Health Officials, "Social Determinants of Health: A Quick Reference Guide for State Offices of Rural Health and State and Territorial Health Officials," September 2017, <https://crh.arizona.edu/sites/default/files/2022-03/Social-Determinants-of-Health-A-quick-reference-guide-for-SORH-and-STHO.pdf>.

<sup>76</sup> American Academy of Pediatrics, "Pediatric Subspecialty Shortages: A Threat to Children's Health," report, n.d., [https://downloads.aap.org/AAP/PDF/Advocacy/Arizona\\_SubspecialtyFactSheet.pdf](https://downloads.aap.org/AAP/PDF/Advocacy/Arizona_SubspecialtyFactSheet.pdf).

<sup>77</sup> Koch B, Coates S, Drake C, and Derksen D. (2022) Arizona Health Workforce Profile: Physician Specialty. [https://crh.arizona.edu/sites/default/files/2022-09/20220824\\_Physician-specialty-WorkforceProfile%5B91%5D.pdf](https://crh.arizona.edu/sites/default/files/2022-09/20220824_Physician-specialty-WorkforceProfile%5B91%5D.pdf).

<sup>78</sup> Ibid.

<sup>79</sup> These counties include Mohave, Coconino, Yavapai, Yuma, Cochise, and Pinal Counties.

<sup>80</sup> These counties include Navajo, Gila, Graham, Apache, Santa Cruz, La Paz, and Greenlee Counties.

<sup>81</sup> Koch B, Coates S, Drake, C, and Derksen D. (2021) Arizona Health Workforce Profile: Critical Care.

source of care and whether a child can receive care when there is a perceived need for care. The barrier of proximity may, therefore, be hindering numerous rural, tribal and/or other minority populations in accessing pediatric healthcare.

### *Quality of Pediatric Healthcare in Arizona*

Quality as well as access is a concern in Arizona. On the Medicaid and CHIP Scorecard Rating,<sup>82</sup> Arizona scored lower than the average state in the quality of healthcare in the following pediatric healthcare areas: adolescent well-care visits (age 12-21); chlamydia screening in women (ages 16-20); well-child visits in the first 15 months of life; well-child visits in the third, fourth, fifth and sixth years of life; and ambulatory care: emergency department visits (ages 0-19).<sup>83</sup>

According to the 2021 report from the National Healthcare Quality and Disparities Report, a report measuring how effectively the healthcare delivery system provides safe, high-quality, and equitable care to all Americans, Arizona fell under the third quartile among the 50 states for disparities in the overall quality of care for Black, Hispanic, Asian/Pacific Islander, Native American/Alaska Natives, and multiracial individuals compared with White individuals.<sup>84</sup> States that fell under the first quartile had the fewest racial and ethnic disparities, while those that fell under the fourth quartile had the most racial and ethnic disparities overall.

### *State Legislation Related to Pediatric Healthcare*

Arizona offers a CHIP Medicaid expansion program, as well as a separate CHIP program called KidsCare.<sup>85</sup> Arizona passed Senate Bill 1726/House Bill 2816 during the 2023 regular session.<sup>86</sup> It made statutory and session law changes relating to healthcare necessary to implement the FY2024 state budget which includes a change to the state's Medicaid qualifications and expanded its parameters for children to get Medicaid coverage from 200 percent to 225 percent of the federal

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<sup>82</sup> The Centers for Medicare & Medicaid Services (CMS) developed its Medicaid and Children's Health Insurance Program (CHIP) Scorecard to increase public transparency about the programs' administration and outcomes. The Medicaid and CHIP Scorecard looks to answer the following questions: 1) Who enrolls in Medicaid and CHIP?; 2) How do states deliver care in Medicaid?; 3) What data are CMS and states developing to support program improvement?; 4) What are annual expenditures for Medicaid and CHIP?; and, 5) What is the rate of improper payments in Medicaid and CHIP?

<sup>83</sup> Mathematica analysis of MACPro reports (as of June 18, 2021), Form CMS-416 reports (as of July 2, 2021), and the Centers for Disease Control and Prevention Wide-ranging Online Data for Epidemiologic Research (CDC WONDER) data (as of November 24, 2020) for the FFY 2020 reporting cycle.

<sup>84</sup> Agency for Healthcare Research and Quality, *NHDR Report 2021*, p. O-39.

<sup>85</sup> Centers for Medicare & Medicaid Services, "CHIP Program Structure by State." <https://www.medicaid.gov/chip/downloads/chip-map.pdf>.

<sup>86</sup> Ariz. S.B. 1726, 56th Leg., 1st Reg. Sess. (2023); Ariz. H.B. 2816, 56th Leg., 1st Reg. Sess. (2023).

poverty level.<sup>87</sup>

The Arizona Department of Health Services is required through the Bureau of Women Children's Health to administer a program of hearing evaluation services to all school-aged children.<sup>88</sup>

In the last five years, the Arizona legislature passed several laws related to pediatric healthcare. In 2018, it passed Bill HB2324, requiring the Arizona Department of Health Services to adopt rules prescribing the scope of practice, minimum qualification, education and training standards, and criteria for certification of community health workers.<sup>89</sup> The following year, they passed a law pertaining to requirements for vision screening. This bill requires vision screening of children in Arizona upon initial entry to school as well as not more than two additional grade levels in a district or charter school that provides preschool and/or K-12 instruction.<sup>90</sup>

Then, in 2021, the Arizona Legislature passed two bills. Senate Bill 1680 requires the Newborn Screening (NBS) Program to include all congenital disorders included on the Recommended Uniform Screening Panel.<sup>91</sup> This allows for an automatic update of the state-required newborn screening list any time the federal government adds more conditions to its recommended list, and expands Arizona's screening list from 31 conditions to all 35 conditions, as federally recommended. Additionally, this bill requires the NBS Program to include all congenital disorders included on the RUSP for both core and secondary conditions.<sup>92</sup>

House Bill 2126, passed on March 23, 2021, added the following language to the Arizona State Loan Repayment Program Rules: "An applicant who works at an Indian Health Service or tribal facility is not required to provide a sliding fee scale to be eligible for the program."<sup>93</sup> Many tribal and IHS facilities do not implement Sliding Fee Schedules because they do not charge IHS-eligible clients for healthcare services rendered. The HB 2126 exemption allows these entities greater participation in the Arizona State Loan Repayment Program without having to implement a Sliding Fee Schedule.

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<sup>87</sup> Ariz. S.B. 1726, 56th Leg., 1st Reg. Sess. (2023); Ariz. H.B. 2816, 56th Leg., 1st Reg. Sess. (2023). [https://www.azleg.gov/legtext/56leg/1R/summary/S.1726-2816APPROP\\_ASENACTED.DOCX.htm](https://www.azleg.gov/legtext/56leg/1R/summary/S.1726-2816APPROP_ASENACTED.DOCX.htm).

<sup>88</sup> A.R.S. 36-899.01.

<sup>89</sup> Ariz. H.B. 2324, 53rd Leg., 2nd Reg. Sess. (2018); "Community Health Workers and Community Health Representatives," n.d., <https://www.azahcccs.gov/CHW>.

<sup>90</sup> A.R.S. 36-899.10.

<sup>91</sup> Ariz. S.B. 1680, 55th Leg., 1st Reg. Sess. (2021).

<sup>92</sup> *Id.*

<sup>93</sup> Ariz. H.B. 2126, 55th Leg., 1st Reg. Sess. (2021) (enacted March 23, 2021) (amending § 36-2174 to exempt applicants working at Indian Health Service or tribal facilities from the requirement to provide a sliding fee scale).

## Findings

In keeping with its duty to inform the Commission of (1) matters related to discrimination or a denial of equal protection of the laws and (2) matters of mutual concern in the preparation of reports of the Commission to the President and the Congress,<sup>94</sup> the Arizona Advisory Committee submits the following findings to the Commission regarding disparities in access to and quality of pediatric care. Findings are defined as what the testimony and other data suggested, revealed, or indicated based upon the data collected by the Committee. Findings refer to a synthesis of observations confirmed by majority vote of members, rather than conclusions drawn by any one member. Therefore, the following findings address civil rights themes that emerged during the Committee's inquiry. The complete meeting transcripts and written testimony received are accessible by a weblink in the footnotes.<sup>95</sup> Additionally, a list of panelists is available in the Appendix.

*Finding I: While the state has made recent strides to expand eligibility to access insurance for low-income Arizona children, Arizona still has a high level of uninsured children.*

As of May 2024, 63,869 Arizona children under the age of 19 are enrolled in KidsCare, the state's version of Medicaid.<sup>96</sup> Most children covered by AHCCCS are on traditional AHCCCS.<sup>97</sup> The program, including the KidsCare population, enrolls roughly 801,400 children ages 0 to 17, which is roughly 37.4 percent of the overall AHCCCS population. AHCCCS enrolls another 146,589 young people ages 18 to 21.<sup>98</sup>

The AHCCCS population has decreased by 12 percent over the past year, partly due to a nationwide trend of Medicaid programs removing individuals from their rolls following post-pandemic policy changes. As of May 2024, the total AHCCCS population stands at 2.2 million,

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<sup>94</sup> 45 C.F.R. § 703.2.

<sup>95</sup> <https://useccr.box.com/s/dwf31qhnjgscvgydf9ctfbz1y89w6z3r>.

<sup>96</sup> "AHCCCS Population Highlights," AHCCCS Population Highlights, May 2024, [https://azahcccs.gov/Resources/Downloads/PopulationStatistics/2024/Highlights\\_050124.pdf](https://azahcccs.gov/Resources/Downloads/PopulationStatistics/2024/Highlights_050124.pdf).

<sup>97</sup> AHCCCS primarily provides health coverage to low-income people typically living at about 138% or less of the federal poverty level and to people with disabilities. Traditional AHCCCS thresholds vary but are generally up to 138% of the federal poverty level, or \$43,056 in annual household income for a family of four. The higher income parameters are what makes the KidsCare program different from traditional Medicaid because it opens up AHCCCS enrollment to the children of working families who have incomes that are higher than the poverty level, but still struggle to pay for essential needs like health care for their children.

<sup>98</sup> "AHCCCS Population Demographics," report, 2024, [https://archive.azahcccs.gov/archive/Resources/Reports/Population%20Statistics/2024/Demographics\\_04012024.pdf](https://archive.azahcccs.gov/archive/Resources/Reports/Population%20Statistics/2024/Demographics_04012024.pdf) (using April 2024 figures).

down from 2.5 million in February 2023.<sup>99</sup> It remains unclear whether all individuals losing AHCCCS coverage are transitioning to alternative health insurance plans. However, Arizona's persistent issue of uninsured children underscores ongoing challenges in ensuring healthcare coverage.

According to Georgetown University's Center for Children and Families report examining 2022 Census Bureau figures, there are 142,000 Arizona children under the age of 19 without health insurance. Arizona has a rate of uninsured children at 8.4 percent and higher than the national average of 5.1 percent. Additionally, the report ranked Arizona fifth highest rate in uninsured children behind Texas, Florida, California, and Georgia.<sup>100</sup>

Racial and ethnic minority children in Arizona are disproportionately uninsured. Based on 2022 Census Bureau figures, 13.6 percent of Native American/Alaska Native children, 12.2 percent of Black children, and 10.3 percent of Latino children were without insurance. In comparison, only 5.9 percent of White children lacked insurance.<sup>101</sup>

Within the Latino community, there are disparities in coverage rates. While most Latino children identify as White (74.9 percent) with an uninsured rate of 10.2 percent, those identifying as Native American/Alaska Native face a significantly higher uninsured rate of 20.6 percent.<sup>102</sup> This suggests the value of targeted, culturally competent outreach in reducing disparities in healthcare coverage.<sup>103</sup>

Arizona's requirement of a five-year waiting period for many legal immigrants before they qualify for Medicaid contributes to high uninsured rates among Latino children and other immigrant communities. Although federal law allows states to waive this waiting period for pregnant women

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<sup>99</sup> "AHCCCS Population Highlights," AHCCCS Population Highlights, May 2024, [https://azahcccs.gov/Resources/Downloads/PopulationStatistics/2024/Highlights\\_050124.pdf](https://azahcccs.gov/Resources/Downloads/PopulationStatistics/2024/Highlights_050124.pdf); "AHCCCS Population Highlights," AHCCCS Population Highlights (AHCCCS, February 2023), [https://archive.azahcccs.gov/archive/Resources/Reports/Population%20Statistics/2023/Highlights\\_02012023.pdf](https://archive.azahcccs.gov/archive/Resources/Reports/Population%20Statistics/2023/Highlights_02012023.pdf).

<sup>100</sup> "Arizona State Profile" Georgetown Center for Children and Families, February 23, 2024, <https://kidshealthcarereport.ccf.georgetown.edu/states/arizona/>; Joan Alker and Aubrianna Osorio, "Medicaid's Pandemic-Era Continuous Coverage Protections Helped Reduce Number of Uninsured Children," Georgetown University Center for Children and Families, November 2023, [https://ccf.georgetown.edu/wp-content/uploads/2023/11/ACS-uninsured-kids-2023\\_11-10-1.pdf](https://ccf.georgetown.edu/wp-content/uploads/2023/11/ACS-uninsured-kids-2023_11-10-1.pdf).

<sup>101</sup> Georgetown University Center for Children and Families analysis of the U.S. Census Bureau 2022 American Community Survey (ACS), Tables C27001A-I: Health Insurance Coverage Status by Age.

<sup>102</sup> Georgetown University Center For Children And Families and Unidos US, "Latino Children's Health Coverage Facts," June 2020, [https://ccf.georgetown.edu/wp-content/uploads/2020/07/UNIDOSUS\\_FactSheet\\_Arizona.pdf](https://ccf.georgetown.edu/wp-content/uploads/2020/07/UNIDOSUS_FactSheet_Arizona.pdf). Note: Georgetown University used U.S. Census Bureau data to determine this finding. Based on the U.S. Census Bureau's questionnaire a respondent is required to answer two questions about Hispanic origin and about race. In 2018, Hispanic origins are not races. See test questionnaire: [https://www2.census.gov/programs-surveys/decennial/2020/program-management/memo-series/2020-memo-2018\\_02\\_questionnaire.pdf](https://www2.census.gov/programs-surveys/decennial/2020/program-management/memo-series/2020-memo-2018_02_questionnaire.pdf).

<sup>103</sup> Ibid.



and children,<sup>104</sup> Arizona has not adopted this waiver, resulting in limited access to essential healthcare for vulnerable populations.<sup>105</sup>

Panelists raised concerns about the many children who were dropped from KidsCare over the years following the pandemic and highlighted the critical need for continuous eligibility.<sup>106</sup> This approach is associated with improved insurance rates, reduced gaps due to application issues, and better access to medical and specialty care, particularly beneficial for children with special healthcare needs.<sup>107</sup>

Recent legislative efforts, such as Senate Bill 1726/House Bill 2816 passed in 2023, expanded insurance eligibility for low-income children by increasing Medicaid coverage from 200 percent to 225 percent of the federal poverty level, and this is expected to provide coverage to 10,000 more children.<sup>108</sup> While these measures aim to extend coverage to an additional 10,000 children, their effectiveness has yet to be evaluated as it was recently enacted on April 1, 2024. Matt Jewett, Director of Health Policy for Children’s Action Alliance emphasized the importance of education and outreach regarding this program.

Even with this expansion, Dr. Darlene Melk, Chief Medical Officer for Chiricahua Community Health Centers, noted that affordability remains a significant hurdle for many children just above the Medicaid threshold, comprising approximately 11.6 percent of Arizona’s child population.<sup>109</sup> Addressing these affordability issues is crucial to ensuring comprehensive healthcare access statewide.

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<sup>104</sup> Centers for Medicare & Medicaid Services, “Medicaid and CHIP Coverage of Lawfully Residing Children & Pregnant Individuals” n.d., <https://www.medicaid.gov/medicaid/enrollment-strategies/medicaid-and-chip-coverage-lawfully-residing-children-pregnant-individuals>.

<sup>105</sup> Michael Ollove, “Enrollment in Health Insurance Lags Among Latino Children,” PBS News, Jun. 28, 2021, <https://www.pbs.org/newshour/health/enrollment-in-health-insurance-lags-among-latino-children>; Kelly Whitener, “Getting Back on Track: A Detailed Look at Health Coverage Trends for Latino Children,” Center for Children and Families, Sept. 2, 2021, <https://ccf.georgetown.edu/2021/06/08/health-coverage-trends-for-latino-children/>.

<sup>106</sup> Derkson Testimony, *6/14/23 Web Briefing*, pp. 20-1; Jewett Testimony, *9/29/23 Web Briefing*, p. 8; Molina Testimony, *3/26/24 Web Briefing*, pp. 19-20.

<sup>107</sup> Brantley E, Ku L. Continuous Eligibility for Medicaid Associated With Improved Child Health Outcomes. *Med Care Res Rev.* 2022 Jun;79(3):404-413. doi: 10.1177/10775587211021172. Epub 2021 Sep 16. PMID: 34525877.

<sup>108</sup> Arizona Health Care Cost Containment System, “Two Medicaid Program Changes Increase Access to Health Care for Children,” Feb. 20, 2024, <https://www.azahcccs.gov/shared/News/PressRelease/IncreasedAccessToChildHealthCare.html>.

<sup>109</sup> Melk Testimony, *2/2/24 Web Briefing*, p. 5.

*Finding II: Foster youth, who are vulnerable to increased prevalence of physical and behavioral needs, are disproportionately impacted by challenges with healthcare access.*

Foster youth and former foster youth have a higher risk of experiencing multiple chronic health conditions and health related social needs, beyond what is associated with socioeconomic instability. This includes increased prevalence of physical and behavioral health needs.<sup>110</sup> Additionally, foster youth frequently experience adverse childhood experiences – such as abuse, neglect, domestic violence, and parental substance abuse – that increase the risk of serious health problems in later life, including severe obesity, diabetes, heart disease, cancer, stroke, chronic obstructive pulmonary disease, and broken bones.<sup>111</sup>

Foster youth are disproportionately affected by healthcare access challenges due to several factors:

<sup>110</sup> Ahrens KR, Garrison MM, Courtney ME. Health outcomes in young adults from foster care and economically diverse backgrounds. *Pediatrics*. 2014 Dec;134(6):1067-74. doi: 10.1542/peds.2014-1150. Epub 2014 Nov 3. PMID: 25367543; PMCID: PMC4243069.

<sup>111</sup> Ibid; Children’s Bureau, National Youth in Transition Database, “Data Brief #6: Comparing Outcomes Reported by Young People at Ages 17 and 19 in NYTD Cohort 2,” November 2017, [https://www.acf.hhs.gov/sites/default/files/documents/cb/nytd\\_data\\_brief\\_6.pdf](https://www.acf.hhs.gov/sites/default/files/documents/cb/nytd_data_brief_6.pdf); Centers for Disease Control and Prevention, “About Adverse Childhood Experiences,” Adverse Childhood Experiences (ACEs), May 16, 2024, <https://www.cdc.gov/aces/about/index.html>; Courtney, M., Dworsky, A., Brown, A., Cary, C., Love, K., & Vorhies, V. (2011). *Midwest evaluation of the adult functioning of former foster youth: Outcomes at age 26*. Chicago, IL: Chapin Hall at the University of Chicago, <https://www.chapinhall.org/wp-content/uploads/Midwest-Eval-Outcomes-at-Age-26.pdf>; Adoption and Foster Care Analysis and Reporting System (AFCARS) FY2017data<sup>2</sup>, <https://www.acf.hhs.gov/sites/default/files/documents/cb/afcarsreport25.pdf>; Children’s Bureau, National Youth in Transition Database, “Data Brief #5: Highlights From the NYTD Survey: Outcomes Reported by Young People at Ages 17, 19, and 21,” November 2016, [https://www.acf.hhs.gov/sites/default/files/documents/cb/nytd\\_data\\_brief\\_5.pdf](https://www.acf.hhs.gov/sites/default/files/documents/cb/nytd_data_brief_5.pdf); Community Catalyst, “The ACA and Former Foster Youth: Opportunities and Challenges for States,” May 2014, <https://www.communitycatalyst.org/wp-content/uploads/2022/11/Foster-Youth-final-1.pdf?1401306962>; Campbell JA, Walker RJ, Egede LE. Associations Between Adverse Childhood Experiences, High-Risk Behaviors, and Morbidity in Adulthood. *Am J Prev Med*. 2016 Mar;50(3):344-352. doi: 10.1016/j.amepre.2015.07.022. Epub 2015 Oct 21. PMID: 26474668; PMCID: PMC4762720, <https://pubmed.ncbi.nlm.nih.gov/26474668/>; Kym R. Ahrens, Michelle M. Garrison, Mark E. Courtney; Health Outcomes in Young Adults From Foster Care and Economically Diverse Backgrounds. *Pediatrics* December 2014; 134 (6): 1067–1074. 10.1542/peds.2014-1150, <https://publications.aap.org/pediatrics/article-abstract/134/6/1067/33100/Health-Outcomes-in-Young-Adults-From-Foster-Care?redirectedFrom=PDF>; Monnat SM, Chandler RF. Long Term Physical Health Consequences of Adverse Childhood Experiences. *Sociol Q*. 2015 Sep;56(4):723-752. doi: 10.1111/tsq.12107. Epub 2015 Jul 3. PMID: 26500379; PMCID: PMC4617302, <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4617302/>.

- i) Foster youth often experience multiple placement changes, which can disrupt continuity of care,<sup>112</sup> making it difficult to maintain consistent medical treatment and provider relationships.<sup>113</sup>
- ii) The trauma and instability experienced by foster youth often result in complex physical and behavioral health needs. This requires comprehensive and coordinated healthcare services, which can be difficult to access consistently.<sup>114</sup>
- iii) Bureaucratic challenges, such as the need for re-enrollment in Medicaid when aging out of the foster care system, can lead to gaps in health coverage.<sup>115</sup> This was the case prior to 2022 when the state did not automatically renew the eligibility of individuals who were in the foster care system at the time of turning 18 years. Additionally, most children in foster care are insured under Medicaid, but not all providers accept Medicaid<sup>116</sup>
- iv) As foster youth age out of the system at 18, they often lose the support structures provided by the child welfare system. This transition can lead to a loss of health insurance and difficulties in navigating adult healthcare systems.<sup>117</sup>

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<sup>112</sup> Rubin DM, Alessandrini EA, Feudtner C, Localio AR, Hadley T. Placement changes and emergency department visits in the first year of foster care. *Pediatrics*. 2004;114(3):354–360; Natalie McGill, “Making Health a Priority for Children in Foster Care System: Connecting to Care, Wherever Kids Are,” *The Nation’s Health*, September 1, 2016, <https://www.thenationshealth.org/content/46/7/1.2>.

<sup>113</sup> Moira A. Szilagyi, David S. Rosen, David Rubin, Sarah Zlotnik, the COUNCIL ON FOSTER CARE, ADOPTION, AND KINSHIP CARE, the COMMITTEE ON ADOLESCENCE and the COUNCIL ON EARLY CHILDHOOD, Moira A. Szilagyi, David Harmon, Paula Jaudes, V Faye Jones, Paul Lee, Lisa Nalven, Lisa Prock, Linda Sagor, Elaine Schulte, Sarah Springer, Thomas Tonniges, Paula K. Braverman, William P. Adelman, Elizabeth M. Alderman, Cora C. Breuner, David A. Levine, Arik V. Marcell, Rebecca O’Brien, Dina Lieser, Beth DelConte, Elaine Donoghue, Marian Earls, Danette Glassy, Terri McFadden, Alan Mendelsohn, Seth Scholer, Jennifer Takagishi, Douglas Vanderbilt, Patricia Gail Williams; Health Care Issues for Children and Adolescents in Foster Care and Kinship Care. *Pediatrics* October 2015; 136 (4): e1142–e1166. 10.1542/peds.2015-2656.

<sup>114</sup> Leslie LK, Gordon JN, Meneken L, Premji K, Michelmore KL, Ganger W. The physical, developmental, and mental health needs of young children in child welfare by initial placement type. *J Dev Behav Pediatr*. 2005;26(3):177–185; Simms MD, Dubowitz H, Szilagyi MA. Health care needs of children in the foster care system. *Pediatrics*. 2000;106(suppl 4):909–918.

<sup>115</sup> Jewett Testimony, 9/29/23 *Web Briefing*, pp. 6-7.

<sup>116</sup> Natalie McGill, “Making Health a Priority for Children in Foster Care System: Connecting to Care, Wherever Kids Are,” *The Nation’s Health*, Sept. 1, 2016, <https://www.thenationshealth.org/content/46/7/1.2>.

<sup>117</sup> Centers for Medicare & Medicaid Services, “Improving Timely Health Care for Children and Youth in Foster Care,” <https://www.medicare.gov/medicaid/quality-of-care/quality-improvement-initiatives/foster-care-learning-collaborative/index.html>.

In Arizona, about 12,000 children are in “out-of-home” care,<sup>118</sup> according to statistics from the Arizona Department of Child Safety (DCS),<sup>119</sup> with Black and Native American children overrepresented in the system when compared with the general population.<sup>120</sup> In 2021, the DCS showed that Black children made up 16.2 percent of the 13,500 children in state care.<sup>121</sup> Native Americans added another 8.2 percent.<sup>122</sup> Those figures are much higher than the share of Black and Native American children in the overall population of 1.6 million children under age 18, 5.7 percent and 5.8 percent, respectively.<sup>123</sup> In contrast, while 48 percent of Arizona’s child population is White, just 31 percent of the children in DCS care are White.<sup>124</sup> Likewise, Hispanic children account for 32.6 percent of the children in DCS care, compared to making up 43 percent of the state’s 1.6 million children under age 18, U.S. Census figures show.<sup>125</sup>

On a county level, recent data indicates that children in Maricopa County have the greatest risk among the 20 largest metro areas of being sent into foster care.<sup>126</sup> For Black and Native American children, the risk is nearly double when measured against the risk for all children in the greater Phoenix area: about one in six face the prospect of being put in foster care, according to the study, published earlier this year by the National Academy of Sciences.<sup>127</sup>

Nationally, similar disparities exist among racial and ethnic groups. According to the Annie E. Casey Foundation, in 2020, Black children represented 20 percent of those entering foster care but

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<sup>118</sup> According to the Arizona Department of Child Safety, out-of-home care refers to any type of out-of-home placement, including relative/kinship care, licensed foster care, licensed group home/Residential Treatment Center, Subsidy Program, etc. See Program Policy: Chapter 4: “Out of Home Care,” [https://extranet.azdcs.gov/DCSPolicy/Content/Program%20Policy/04\\_Out\\_of\\_Home\\_Care/Chapter%2004%20Outline.htm](https://extranet.azdcs.gov/DCSPolicy/Content/Program%20Policy/04_Out_of_Home_Care/Chapter%2004%20Outline.htm).

<sup>119</sup> Arizona Department of Child Safety, *Semi-Annual Child Welfare Report Sep 2022*, Sept. 30, 2022, <https://dcs.az.gov/content/semi-annual-child-welfare-report-sep-2022>.

<sup>120</sup> Arizona Department of Child Safety, “Racial Inequity in Child Protection,” Oct. 2, 2020, <https://dcs.az.gov/sites/default/files/documents/files/CAC-RacialInequityinChildProtection-Presentation-10-2-2020.pdf>.

<sup>121</sup> Arizona Department of Child Safety, “Monthly Operational Report,” June 2021, <https://dcs.az.gov/file/16140/download?token=cThkRLxG>.

<sup>122</sup> Ibid.

<sup>123</sup> Ibid.

<sup>124</sup> Mary Jo Pitzl, “In Phoenix Area, 2 Out of 5 Kids Risk a DCS Call. It’s Worse for Black and Native Kids,” Arizona Republic, Dec. 1, 2021, <https://www.azcentral.com/story/news/local/arizona-child-welfare/2021/11/30/phoenix-area-children-face-highest-risk-foster-care-dcs/6381564001/>.

<sup>125</sup> Ibid.

<sup>126</sup> Frank Edwards et al., “Contact With Child Protective Services Is Pervasive but Unequally Distributed by Race and Ethnicity in Large US Counties,” Proceedings of the National Academy of Sciences of the United States of America 118, no. 30 (July 19, 2021), <https://doi.org/10.1073/pnas.2106272118>.

<sup>127</sup> Ibid.

only 14 percent of children in the U.S., while Indigenous children made up 2 percent of those entering care and 1 percent of the overall child population.<sup>128</sup>

Another group of foster youth that is often difficult to survey are LGBTQ youth in foster care. In a 2019 study by Children’s Rights, there is an overrepresentation of LGBTQ youth in foster care, where 30 percent of foster youth identify as LGBTQ+ and 5 percent as transgender, compared to 11 percent and 1 percent, respectively, among LGBTQ youth not in foster care.<sup>129</sup> State data for LGBTQ youth is not widely accessible.

These statistics demonstrate who is affected by the foster care system and implications for continuity of healthcare access as they approach emancipation from the system. Matt Jewett testified about the legislative challenges surrounding continuity of care for foster youth, highlighting the gaps in service they face as they age out of the system. Since the state had not implemented continuous enrollment for those nearing the age limit prior to 2022, many foster youth were at risk of losing their Medicaid coverage.<sup>130</sup> He shared the testimony of a former foster youth who aged out of the system without realizing she was uninsured due to this lack of continuous enrollment, which led to accrued medical debt from gaps in her coverage.<sup>131</sup>

Arizona has a pending Section 1115 amendment to provide multiyear continuing enrollment to former foster youth who have aged out of foster care at age 18 and up to age 26.<sup>132</sup> The AHCCCS letter to the U.S. Centers for Medicare and Medicaid Services requesting the amendment stated:

The Former Foster Youth Annual Automatic Renewal Amendment is designed to complement the existing transitional medical care for children leaving foster care by promoting continuity of care and coverage while also simplifying the administrative process and reducing unnecessary eligibility churn. In combination with Arizona’s approved 1115 waiver programming, this amendment will help address the higher risk of multiple chronic health conditions and health related social needs (HRSN)

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<sup>128</sup> The Annie E. Casey Foundation, “Child Welfare and Foster Care Statistics,” April 7, 2024, <https://www.aecf.org/blog/child-welfare-and-foster-care-statistics>.

<sup>129</sup> “Fact Sheet: LGBTQ+ Youth in the Foster System,” Children’s Rights, January 2023, <https://www.childrensrights.org/wp-content/uploads/2023/12/CR-LGBTQ-Youth-in-Foster-Care-2023-Fact-Sheet.pdf>; Adnan Alam and Chase W. Drumgoole, “‘We See Value in You’: Arizona Organization Helps Bridge Gaps Between Foster Kids and Families,” *Cronkite News*, Nov. 21, 2022, <https://cronkitenews.azpbs.org/2022/11/21/arizona-organization-helps-bridge-gaps-between-foster-kids-and-families/>.

<sup>130</sup> Jewett Testimony, *9/29/23 Web Briefing*, pp. 6-7.

<sup>131</sup> *Ibid.*

<sup>132</sup> Letter directed to the U.S. Centers for Medicare and Medicaid Services from the Arizona Health Care Cost Containment System, Mar. 28, 2023, <https://www.azahcccs.gov/Resources/Downloads/Federal/FinalAHCCCSFormerFosterYouthWaiverAmendmentProposal.pdf>.

experienced by the foster youth and former foster youth including but not limited to an increased prevalence of physical and behavioral health needs and higher rates of homelessness.<sup>133</sup>

The amendment proposal was submitted in alignment with House Bill 2622<sup>134</sup> that was signed by Governor Hobbs in 2022. The bill allows AHCCCS to automatically renew the eligibility of individuals who were in DCS care at the time of turning 18 years, without requiring additional information until the person reaches 26 years.<sup>135</sup> If approved, the waiver amendment would be in place for five years and would promote the continuity of care and simplify administrative work.<sup>136</sup>

*Finding III: Across the state, there is a shortage of healthcare providers which raises concern for widening disparities in access among demographic groups to routine and specialty care.*

The Arizona healthcare system has faced an ongoing shortage of personnel for the past twenty years.<sup>137</sup> The COVID-19 pandemic exacerbated this shortage in all areas of healthcare and Arizona has fallen below the national average of workers in almost all healthcare professions.<sup>138</sup> The Health Professional Shortage Areas (HPSA) designation system used and created by the Health Resources & Services Administration, an agency of the Department of Health and Human Services helps to identify areas with shortages of healthcare providers.<sup>139</sup> HPSAs are scored from 0-25 with scores closer to 0 indicating a lower priority while a score closer to 25 indicating a higher priority.<sup>140</sup> In 2021, Arizona had a total of 644 federally designated HPSAs, including 220 for primary care, 211 for dental, and 213 for mental health designations.<sup>141</sup> Additionally, there were 37 Medically Underserved Areas and 10 Medically Underserved Population designations.<sup>142</sup> To eliminate these shortages, the state would need to hire an additional 558 full-time primary care physicians, 381 dentists, and 178 psychiatrists.<sup>143</sup> In 2023, the Arizona Department of Health Services reported to

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<sup>133</sup> Häggman-Laitila, A., Salokekkilä, P. & Karki, S. Young People’s Preparedness for Adult Life and Coping After Foster Care: A Systematic Review of Perceptions and Experiences in the Transition Period. *Child Youth Care Forum* 48, 633–661 (2019). <https://doi.org/10.1007/s10566-019-09499-4>.

<sup>134</sup> Ariz. H.B. 2622, 55th Leg., 2nd Reg. Sess. (2022).

<sup>135</sup> *Id.*

<sup>136</sup> *Id.*

<sup>137</sup> “The Arizona Healthcare Workforce Shortage,” Arizona Health Workforce, <https://azhealthworkforce.org/the-arizona-healthcare-workforce-shortage/>.

<sup>138</sup> *Ibid.*

<sup>139</sup> U.S. Department of Health and Human Services, Health Resources & Services Administration, “What Is Shortage Designation? | Bureau of Health Workforce,” June 1, 2023. <https://bhw.hrsa.gov/workforce-shortage-areas/shortage-designation>.

<sup>140</sup> *Ibid.*

<sup>141</sup> Arizona Department of Health Services, 2021 Arizona Primary Care Needs Assessment, p. 4.

<sup>142</sup> *Ibid.*

<sup>143</sup> *Ibid.*

HRSA 685 federally designated HPSAs across primary care, dental, and mental health services.<sup>144</sup> Updated state hiring would require an additional 653 primary care physicians, 406 dentists, and 217 psychiatrists to meet current demand.<sup>145</sup>

In rural areas, where 15 percent of the population is Native American, and more than half of Arizona's 15 counties include reservation lands within their borders, shortages are pronounced.<sup>146</sup> The Center for Rural Health's 2023 physician workforce report noted that Arizona has primary care physician shortages in all counties, and is worse in rural areas.<sup>147</sup> For instance, the White Mountain and San Carlos Apache Reservations each have an HPSA score of 21,<sup>148</sup> indicating high priority and the highest among Arizona's tribal nations.<sup>149</sup> Additionally, there are 74 designated IHS, Tribal Health, and Urban Indian Health Facility Primary Care HPSAs.<sup>150</sup> According to Gerilene Haskon, Tribal Liaison for the Arizona Department of Health Services, the shortages are severe for the Native American community because 12 of Arizona's medically underserved areas are located within Native American tribal lands. She noted that shortages of primary care physicians, dentists, psychiatrists, pediatricians, and OB-GYNs contribute to disparities in care. Additionally, the shortage of healthcare professionals in these areas is compounded by the geographic isolation, socioeconomic challenges faced by these communities, and limited means of communication.<sup>151</sup>

Healthcare shortages during COVID-19 pandemic on rural communities offers a clear example of its impact. The pandemic further highlighted critical nursing shortages, affecting patient care in intensive care units. Before the pandemic, Arizona was facing a shortage of nearly 600 physicians, but as COVID-19 spread around the world, rural communities were hit hardest due to lack of

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<sup>144</sup> U.S. Department of Health and Human Services, Health Resources and Services Administration, "Arizona - 2023 - III.A.1. Program Overview – 2023," <https://mchb.tvisdata.hrsa.gov/Narratives/ExecutiveSummary/baf8d71f-c427-4aa4-a5de-54f3ff482f62> (hereafter cited as Health Resources and Services Administration, *Arizona - 2023 - III.A.1. Program Overview – 2023*).

<sup>145</sup> Ibid.

<sup>146</sup> Koch, B, Drake, C, Garn, A. and Derksen, D. 2023. Describing The Primary Care Shortage in Arizona, [https://crh.arizona.edu/sites/default/files/2023-05/230531\\_PCHPSA\\_Brief.pdf](https://crh.arizona.edu/sites/default/files/2023-05/230531_PCHPSA_Brief.pdf).

<sup>147</sup> Ibid.

<sup>148</sup> The Health Professional Shortage Areas designation system is used by the Department of Health and Human Services to identify areas with shortages of healthcare providers. HPSAs can be geographic areas, populations, or facilities with a shortage of primary, dental, or mental healthcare providers. The scores are determined by population to provider ratio, percentage of the population below 100% of the Federal Poverty Level, Infant Health Index and travel time to the nearest source of care. HPSAs are scored from 0-25 with scores closer to 0 indicating a lower priority while a score closer to 25 indicating a higher priority. See <https://bhw.hrsa.gov/workforce-shortage-areas/shortage-designation/scoring>.

<sup>149</sup> Ibid.

<sup>150</sup> Health Resources and Services Administration, "HPSA Find," n.d., <https://data.hrsa.gov/tools/shortage-area/hpsa-find>.

<sup>151</sup> Haskon Testimony, 3/26/24 *Web Briefing*, p. 11.

access to healthcare and healthcare personnel.<sup>152</sup> For example, Apache County had the highest excess death rate of any large county nationwide in both 2020 and 2021, while neighboring Navajo County had the fourth-highest rate in 2020 and second highest in 2021.<sup>153</sup>

Shortages exist in specialty care which adds another layer of difficulty for families to obtain the care their children need. Dr. Helene Felman, Division Chief of General Pediatrics and Clinical Associate Professor of Pediatrics for the University of Arizona Tucson, testified to the dire situation for pediatric rheumatology patients, noting that families may need to travel up to 246 miles for care depending on where they live.<sup>154</sup> Obtaining this care is particularly challenging for underrepresented and under resourced families because they face barriers to transportation and the ability to take time off from work if they are lucky enough to get an appointment. She noted:

This is a microcosm of the broader issue affecting the state. The lack of pediatric specialists is a stark indicator of the broader inadequacies in Arizona's healthcare system, particularly in rural regions where the infrastructure to support specialized medical practices is often lacking.<sup>155</sup>

According to researchers Kreider, et al., children with all insurance types experienced challenges in access to specialty care, with caregivers of children insured by CHIP reporting the highest rates of difficulty accessing specialty care, problems obtaining a referral, and frustration obtaining healthcare services.<sup>156</sup>

Panelists offered additional context regarding the supply and demand of healthcare professionals. Dr. Daniel Derksen, Professor of Public Health, Medicine & Nursing and Associate Vice President for Health Equity, Outreach & Interprofessional Activities at the University of Arizona, pointed out that Arizona's population has surged by 44 percent over the past two decades, adding more than 2 million new residents, while the healthcare workforce has struggled to keep pace with this rapid growth.<sup>157</sup> In an analysis by the Association of American Medical Colleges, Arizona ranks 42nd in primary care physicians per capita.<sup>158</sup> Additionally, the Health Resources and Services

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<sup>152</sup> Blair Willis, "Addressing Arizona's Rural Physician Shortage," Center for Rural Health, Nov. 15, 2023, <https://crh.arizona.edu/news/addressing-arizonas-rural-physician-shortage>.

<sup>153</sup> Ibid.

<sup>154</sup> Felman Testimony, *6/14/23 Web Briefing*, pp. 15-6.

<sup>155</sup> Ibid.

<sup>156</sup> Amanda R. Kreider et al., "Quality of Health Insurance Coverage and Access to Care for Children in Low-Income Families," *JAMA Pediatrics* 170, no. 1 (January 1, 2016): 43, <https://doi.org/10.1001/jamapediatrics.2015.3028>.

<sup>157</sup> Derksen Testimony, *6/14/24 Web Briefing*, pp. 3-4.

<sup>158</sup> Physician Masterfile (December 31, 2020). Population estimates as of July 1, 2019 are from the U.S. Census Bureau (Release date: December 2019); Association of American Medical Colleges, "Arizona Physician Workforce Profile," 2021, <https://www.aamc.org/media/58126/download>.



Administration project that if current trends persist, the state will have a shortage of 2,000 primary care physicians by 2030.<sup>159</sup>

A viable pipeline of physicians is a serious concern both nationally and in Arizona. The Medicare Graduate Medical Education (GME) program was enacted to ensure a sufficient supply of well-trained physicians.<sup>160</sup> However, the current cap on Medicare-supported residency positions, imposed by the Balanced Budget Act of 1997, restricts the number of positions for which teaching hospitals can receive direct GME funding and the amount of indirect graduate medical education funding they receive.<sup>161</sup> Graduate medical training is subsidized by federal Medicare and state-federal Medicaid funding.<sup>162</sup> On a statewide level, Arizona reduced its primary care residency slots from 2016 to 2019, and in effect, widened the gap in healthcare access.<sup>163</sup> Also, many medical graduates train out-of-state, with only 25 percent returning.<sup>164</sup> This contributes to disparities in access to healthcare, particularly in tribal areas, which cover nearly a quarter of the state's landmass and have high Health Professional Shortage Area scores, reaching as high as 20 on a scale of 25.<sup>165</sup> With this context in mind, Dr. Derksen advocated for the state to expand residency slots, particularly in primary care, with a target of 1,100 new slots to align with population needs as it addresses the critical need for balanced investment in both primary care and specialty residency programs to meet the healthcare demands of Arizona's growing population effectively.<sup>166</sup>

To address the pipeline of physicians, the Arizona Board of Regents launched the initiative "AZ Healthy Tomorrow: A Bold Initiative for Arizona's Healthy Future" to create new medical schools at Arizona State University (ASU) and Northern Arizona University (NAU).<sup>167</sup> The ASU medical

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<sup>159</sup> Health Resources and Services Administration (HRSA). December 2022. Designated Health Professional Shortage Areas Statistics 2022. Accessed February 9, 2023.

<https://data.hrsa.gov/Default/GenerateHPSAQuarterlyReport>; Derksen D, Koch B, Garn A, Barraza L: Arizona Graduate Medical Education (GME) Policy Brief. University of Arizona Center for Rural Health, [https://crh.arizona.edu/sites/default/files/2023-06/230601\\_GME\\_Arizona\\_Brief.pdf](https://crh.arizona.edu/sites/default/files/2023-06/230601_GME_Arizona_Brief.pdf). Updated 05/31/2023.

<sup>160</sup> Congressional Budget Office, *Medicare and Graduate Medical Education*, 1995, <https://www.cbo.gov/sites/default/files/104th-congress-1995-1996/reports/Gradmede.pdf>; 1965 Social Security Act (Senate Report No. 404, Pt. 1, 89th Congress, 1st Sess. 36 [1965]; H.R. No. 213, 89th Cong., 1st Sess. 32 [1965]).

<sup>161</sup> U.S. Government Accountability Office, "Caps on Medicare-Funded Graduate Medical Education at Teaching Hospitals," May 2021, GAO-21-391, <https://www.gao.gov/assets/gao-21-391.pdf>.

<sup>162</sup> Ibid.

<sup>163</sup> Health Resources and Services Administration (HRSA). Area Health Resources File. <https://data.hrsa.gov/topics/health-workforce/ahrf>.

<sup>164</sup> Derksen Testimony, *6/14/24 Web Briefing*, p. 4.

<sup>165</sup> Derksen D, Koch B, Garn A, Barraza L: Arizona Graduate Medical Education (GME) Policy Brief. University of Arizona Center for Rural Health. Updated 02/15/2023. [https://crh.arizona.edu/sites/default/files/202302/230215\\_GME\\_Arizona\\_Brief.pdf](https://crh.arizona.edu/sites/default/files/202302/230215_GME_Arizona_Brief.pdf).

<sup>166</sup> Derksen Testimony, *6/14/24 Web Briefing*, pp. 5, 34.

<sup>167</sup> Arizona Board of Regents, "AZ Healthy Tomorrow", <https://www.azregents.edu/azhealthytomorrow>.

school will focus on technology, medical engineering, and biomedical sciences and the NAU medical school will focus on primary care for rural, underserved, and Indigenous communities.<sup>168</sup>

In addition to the shortage of residency slots, medical students who take out loans for their education face the daunting challenge of repaying hundreds of thousands of dollars in debt. A crucial decision that affects their potential earnings is choosing their area of practice and this decision has important consequences for the shortage of healthcare providers in the state.<sup>169</sup> Primary care, for instance, has a lower reimbursement rate compared to other specialties.<sup>170</sup> Continued investment in graduate medical education and expanding Medicare-funded residency slots can be effective approaches to address workforce shortages.<sup>171</sup> Specifically, the state can offer tax credits for healthcare providers to work in shortage areas and implement state-funded tuition programs to incentivize physicians to practice in underserved communities.<sup>172</sup> Likewise on a federal level, funding the National Health Services Loan Repayment program and the Conrad 30 waiver program, which provide federal funding to incentivize healthcare professionals to work in underserved areas, can help mitigate shortages in critical healthcare roles.<sup>173</sup> Currently, there are limitations on the number of providers that can be supported through these initiatives.<sup>174</sup> By allocating additional resources, more healthcare professionals could be encouraged to practice in areas facing significant shortages, thereby enhancing access to care for underserved communities.<sup>175</sup>

Additionally, Dr. Murray Feldstein, Visiting Fellow at the Goldwater Institute testified to the reasons for shortages in several medical specialties. He raised concerns about regulations in postgraduate education that influence graduate numbers and variety of those obtaining medical degrees and certifications. To address the shortage, he recommended licensing reforms to promote competence-based certification, including empowering state boards to certify competence and evaluate and discipline practitioners.<sup>176</sup>

Related to the shortage of healthcare professionals is workforce development. Dr. Derksen noted that programs with teaching health center models play a critical role in addressing shortages in healthcare professions, with 80 percent of graduates remaining in primary care and more than half

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<sup>168</sup> Ibid.

<sup>169</sup> Derksen Testimony, *6/14/24 Web Briefing*, p. 38.

<sup>170</sup> Michelle Andrews, “Compensation Is Key to Fixing Primary Care Shortage - KFF Health News,” KFF Health News, Nov. 16, 2023, <https://kffhealthnews.org/news/article/compensation-pay-primary-care-shortage-solution/>.

<sup>171</sup> Felman Testimony, *6/14/24 Web Briefing*, pp. 39-40.

<sup>172</sup> Derksen Testimony, *6/14/24 Web Briefing*, p. 32.

<sup>173</sup> Ibid., Haskon Testimony, *3/26/24 Web Briefing*, p. 21.

<sup>174</sup> Haskon Testimony, *3/26/24 Web Briefing*, p. 21.

<sup>175</sup> Ibid.

<sup>176</sup> Feldstein Testimony, *9/29/23 Web Briefing*, pp. 14-6.

practicing in shortage areas.<sup>177</sup> Funding for programs with a teaching health center model receive less funding. For instance, in 2022 the U.S. Department of Health and Human Services' Health Resources and Services Administration funding provided \$155 million<sup>178</sup> compared to \$25 billion in GME subsidies largely to urban, specialty hospitals.<sup>179</sup>

Efforts to address shortages over the last two decades have varied in approaches. Recent legislative appropriations of \$5 million aim to establish new primary care residency programs in rural areas, focusing on federally qualified health centers, Indian Health Service sites, tribal-operated facilities, and rural health clinics.<sup>180</sup> This initiative aims to train more pediatricians and other primary care providers in underserved areas, supported by Arizona's expanded Area Health Education Center (AHEC) system, including the new Native American Health AHEC Regional Center.<sup>181</sup> Offering alternatives to care through telemedicine was also bolstered especially during the pandemic.

*Finding IV: There is a need for better data collection in virtually every area of pediatric healthcare. In doing so, this would allow for targeted interventions, especially for vulnerable groups of children.*

Improving data collection in pediatric healthcare is essential for targeted interventions, especially for vulnerable groups of children. Dr. Page testified about the difficulties in obtaining comprehensive data to evaluate disparities in pediatric healthcare. Although the Early Hearing Detection and Intervention program collects data on various variables such as race, ethnicity, and maternal education, significant limitations exist regarding the availability and quality of this data. Information on geographic location, insurance type, congenital infections, and language spoken is either not documented or is not easily extractable from the data.<sup>182</sup> Additionally, recent data and geographic information are hard to obtain due to privacy and data management concerns.<sup>183</sup> Due to this challenge, Dr. Page emphasized the necessity for better coordination and more streamlined processes to access and analyze data, and called for an organized effort to enhance data availability

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<sup>177</sup> Derksen Testimony, 6/14/24 Web Briefing, p. 8.

<sup>178</sup> U.S. Department of Health and Human Services, Health Resources and Services Administration, "Teaching Health Center Graduate Medical Education (THCGME) Academic Year 2022-2023 Awardees," July 1, 2022, <https://bhwh.hrsa.gov/funding/apply-grant/teaching-health-center-graduate-medical-education/ay2022-2023-awardees>.

<sup>179</sup> Derksen Testimony, 6/14/24 Web Briefing, p. 8.

<sup>180</sup> Ariz. S.B. 1727, 56th Leg., 1st Reg. Sess. (2023); Ibid.

<sup>181</sup> Ibid.

<sup>182</sup> Page Testimony, 9/26/23 Web Briefing, pp. 21-2.

<sup>183</sup> Ibid.

on relevant variables, standardize reporting, and improve collaboration among stakeholders to address disparities effectively.<sup>184</sup>

Evaluating other states' approaches to data collection can suggest best practices to identify disparities and implement targeted interventions. For example, Iowa, Kansas, and Illinois have successfully used their data for this purpose. Data for Black children living in Illinois revealed that 25 percent are more likely to be lost to follow-up, enabling targeted interventions for this population.<sup>185</sup>

Research has shown that disparities in pediatric healthcare are often exacerbated by socioeconomic factors. For instance, a study published in *JAMA Pediatrics* found that children from low-income families were less likely to receive timely and adequate healthcare services, leading to poorer health outcomes.<sup>186</sup> Specifically in Arizona, Native American families lack access to pediatric audiology services, which leads to delays in care and poorer outcomes.<sup>187</sup> This specific disparity can likely be addressed with better data-informed interventions.<sup>188</sup>

There are unique challenges with data collection regarding utilization among the Native American community specifically, due to lack of claims data. Allison Lovell testified to the unique billing and funding mechanisms of IHS and 638 clinics.<sup>189</sup> IHS hospitals and clinics are funded and operated by the federal government, providing healthcare services to Native Americans and Alaska Natives across the United States.<sup>190</sup> On the other hand, 638 clinics operate under the Indian Self-Determination and Education Assistance Act,<sup>191</sup> which allows tribes to contract with the federal government to administer healthcare programs themselves. These 638 clinics receive federal funding but are managed and operated by tribal governments or organizations.<sup>192</sup> When a family or individual accesses these facilities and receives multiple services during a visit, the facility

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<sup>184</sup> Page Testimony, *9/26/23 Web Briefing*, p. 20.

<sup>185</sup> *Ibid.*, p. 26.

<sup>186</sup> Bettenhausen JL, Colvin JD, Berry JG, et al. Association of Income Inequality With Pediatric Hospitalizations for Ambulatory Care–Sensitive Conditions. *JAMA Pediatr.* 2017;171(6):e170322. doi:10.1001/jamapediatrics.2017.0322; Lovell Testimony, *3/26/24 Web Briefing*, pp. 15-7.

<sup>187</sup> Page Testimony, *9/26/23 Web Briefing*, p. 26.

<sup>188</sup> *Ibid.*

<sup>189</sup> Lovell Testimony, *3/26/24 Web Briefing*, pp. 7-8.

<sup>190</sup> Indian Health Service, "About IHS | Indian Health Service (IHS)," About IHS, n.d., <https://www.ihs.gov/aboutihs/>.

<sup>191</sup> Public Law 93-638.

<sup>192</sup> Indian Health Service, "Find Health Care | Indian Health Service (IHS)," Find Health Care, n.d., <https://www.ihs.gov/findhealthcare/>.

aggregates these services into a blanket revenue code called the “All-inclusive Rate” (AIR).<sup>193</sup> This billing approach, while intended to streamline the billing process, results in limited specificity in claims data, making it hard to assess healthcare utilization accurately. For instance, if a patient visits a 638 clinic for multiple services, the billing reflects the AIR. In contrast, at a non-IHS or non-638 clinic, each task or service provided to the patient—including medical, surgical, and diagnostic services—is individually coded to ensure uniformity in billing for Medicare and Medicaid.<sup>194</sup>

Addressing the unique healthcare challenges faced by Native American children often necessitates tribes applying for grants to fund targeted interventions.<sup>195</sup> However, limited data availability often hinders their ability to secure these grants, placing them at a disadvantage.<sup>196</sup>

Many tribal healthcare facilities operate independently of state systems, resulting in fragmented data.<sup>197</sup> Allison Lovell testified that respecting tribal sovereignty is critical in data collection efforts.<sup>198</sup> Building trust and establishing partnerships are essential to facilitate data sharing while respecting tribal sovereignty.<sup>199</sup> Engaging and collaborating with tribal leaders and healthcare providers ensures accurate and respectful data collection.<sup>200</sup>

Enabling tribes to have access to national or state-level platforms for managing their data and health needs could help support these efforts. Such platforms could improve the ability to share context-specific data, highlighting areas that require additional focus or resources.<sup>201</sup>

### *Findings Related to the Native American Community*

*Finding V: Native American children and their families, who live in both rural and urban settings, experience varying challenges in accessing healthcare and receiving quality healthcare.*

Native American children and their families face many challenges including socioeconomic, geographic, and systemic barriers that contribute to significant disparities in health outcomes.

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<sup>193</sup> Lovell Testimony, *3/26/24 Web Briefing*, pp. 7-8.

<sup>194</sup> Ibid.

<sup>195</sup> Lovell Testimony, *3/26/24 Web Briefing*, p. 16.

<sup>196</sup> Ibid.

<sup>197</sup> Lovell Testimony, *3/26/24 Web Briefing*, pp. 15-7; Haskon Testimony, *3/26/24 Web Briefing*, pp. 12-3.

<sup>198</sup> Lovell Testimony, *3/26/24 Web Briefing*, pp. 15-7.

<sup>199</sup> Ibid., Haskon Testimony, *3/26/24 Web Briefing*, pp. 12-3.

<sup>200</sup> Ibid.

<sup>201</sup> University of Arizona, Native Nations Institute, “Indigenous Data Sovereignty and Governance,” <https://nni.arizona.edu/our-work/research-policy-analysis/indigenous-data-sovereignty-governance>.

Gerilene Haskon, Tribal Liaison at the Arizona Department of Health Services emphasized that Native American and Alaska Native populations face significant barriers to accessing healthcare.<sup>202</sup> Data indicates that these communities are less likely to have health insurance or access to preventative care compared to non-Hispanic Whites.<sup>203</sup> This is a critical issue, as it can lead to untreated health conditions becoming more severe and costly to address later on.<sup>204</sup> Additionally, there are disparities in developmental testing and the transition from pediatric to adult healthcare, further complicating health for Native American children.<sup>205</sup>

A significant portion of healthcare for Native American communities is provided through the 23 federally funded IHS facilities.<sup>206</sup> However, the availability and quality of services at these facilities can vary widely, and there are often significant gaps in services, especially in remote or rural areas. For instance, children on the Hopi Nation reservation might not have access to the same variety of services as those living in Phoenix, regardless of their insurance status.<sup>207</sup> IHS provides healthcare services to Native Americans and Alaska Natives either directly through a system of federally operated facilities, or indirectly through facilities that are operated by Tribes or others.<sup>208</sup> Yet, there are often significant gaps in service provision, especially in remote or rural areas. For instance, while urban centers may offer a broader range of healthcare services, rural areas might lack specialized care, forcing families to travel long distances to receive appropriate treatment.<sup>209</sup>

The geographic distribution of Native American populations also plays a crucial role in healthcare access. Native American children live both on reservations and in urban areas, with those in rural or tribal regions often facing more severe access issues. Matt Jewett noted that maintaining

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<sup>202</sup> Haskon Testimony, 3/26/24 *Web Briefing*, pp. 11-2.

<sup>203</sup> Kids Count Data Center, <https://datacenter.aecf.org/data/line/10196-children-without-health-insurance-by-race-and-ethnicity?loc=1&loct=1#2/4/false/1095,2048,1729,37,871/asc/187/19729>, Population Reference Bureau analysis of data from the U.S. Census Bureau, American Community Survey table C27001.

<sup>204</sup> Latoya Hill and Samantha Artiga, “Health Coverage Among American Indian and Alaska Native and Native Hawaiian and Other Pacific Islander People,” KFF, November 30, 2023, <https://www.kff.org/racial-equity-and-health-policy/issue-brief/health-coverage-among-american-indian-and-alaska-native-and-native-hawaiian-and-other-pacific-islander-people/>.

<sup>205</sup> Haskon Testimony, 3/26/24 *Web Briefing*, p. 11.

<sup>206</sup> Indian Health Service, “Locations,” <https://www.ihs.gov/locations/>.

<sup>207</sup> Jewett Testimony, 9/29/23 *Web Briefing*, pp. 9-10.

<sup>208</sup> In addition to federally operated facilities, some federally recognized Tribes choose to operate their own health care facilities and receive IHS funding. When services are unavailable at federally operated or tribally operated facilities, IHS may pay for services provided through private providers through its Purchased/Referred Care program. IHS also provides funding to nonprofit, urban Indian organizations through the Urban Indian Health program to provide health care services to American Indian and Alaska Native people living in urban areas. See 25 U.S.C. § 1653.

<sup>209</sup> Jewett Testimony, 9/29/23 *Web Briefing*, pp. 9-10.

Medicaid coverage can be particularly challenging for these families, as any changes to their Medicaid status are typically communicated through the mail.<sup>210</sup> In remote areas, mail delivery can be unreliable, and access to community assistors who can help with Medicaid enrollment is limited.<sup>211</sup> This makes it difficult for families to maintain continuous healthcare coverage, leading to gaps in care.<sup>212</sup>

Specialty care shortages are another significant barrier for Native American children. Dr. Felman pointed out that parents concerned about their child's speech delay or potential autism face extremely long wait times for behavioral or developmental care, especially in states like Arizona.<sup>213</sup> Referrals can take six to twelve months, with an average travel distance of 248 miles. Post-diagnosis, there is an additional four to six months wait for therapies due to a shortage of healthcare providers.<sup>214</sup> These delays can be detrimental, particularly for early intervention in developmental conditions, underscoring the urgent need to address specialty care shortages.<sup>215</sup>

Telehealth has emerged as a potential solution to some of these challenges, particularly in rural areas. The pandemic has accelerated the adoption of telehealth, making it more accessible for patients who might otherwise struggle to receive care.<sup>216</sup> Dr. Derksen noted that Arizona has been a leader in telehealth services through Medicaid, which is crucial for healthcare access in remote regions.<sup>217</sup> The federal government's investment in expanding broadband in the state is a critical step towards improving telehealth capabilities. Ensuring that telehealth remains a viable option post-pandemic, by continuing exemptions and enhancing internet infrastructure, could significantly enhance healthcare access for Native American communities.<sup>218</sup> Such care for certain types of appointments is helpful, but it cannot fully substitute for in-person care, especially for complex medical needs, reinforcing the need to increase access to healthcare facilities and medical professionals.<sup>219</sup>

Finally, education and outreach are essential to improving healthcare access for Native American families. Dr. Derksen emphasized that many Native Americans remain uninsured due to a lack of

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<sup>210</sup> Ibid.

<sup>211</sup> Ibid.

<sup>212</sup> Ibid., p. 8.

<sup>213</sup> Felman Testimony, *6/29/23 Web Briefing*, pp. 15-6.

<sup>214</sup> Ibid.

<sup>215</sup> Ibid.

<sup>216</sup> Ibid., p. 19.

<sup>217</sup> Derksen Testimony, *6/29/23 Web Briefing*, pp. 20-1.

<sup>218</sup> Ibid.

<sup>219</sup> Haskon Testimony, *3/26/24 Web Briefing*, p. 13; Molina Testimony, *3/26/24 Web Briefing*, p. 22-3.

awareness about their eligibility for Medicaid and other programs.<sup>220</sup> Misconceptions about IHS coverage deter enrollment in additional insurance, which is crucial for accessing specialized services not available at IHS facilities.<sup>221</sup> Improving eligibility and enrollment systems ensuring a “no wrong door” approach can enhance healthcare access and improve outcomes for Native American children.<sup>222</sup> Additionally, educating families about available benefits and simplifying enrollment processes are key steps to improving healthcare access and financial stability for IHS and tribe-operated sites.<sup>223</sup>

*Finding VI: A holistic approach and cultural competency to pediatric care is beneficial to Native American children.*

Panelists discussed the need for a holistic approach<sup>224</sup> and cultural competency<sup>225</sup> in treating Native American children. Dr. John Molina, Director for the Arizona Advisory Council on Indian Health Care testified to the alarming rise of obesity and related cardiovascular disorders among Indigenous youth in Arizona, stressing that these health disparities are related to their consumption of non-traditional foods.<sup>226</sup> He emphasized the need to address these health issues by advocating for a return to traditional foods as they are not only nutritionally valuable, but also hold sacred significance and play a crucial role in healing.<sup>227</sup> By reconnecting with Indigenous traditions and embracing self-determination, communities can combat the health challenges exacerbated by the Western way of life.<sup>228</sup> Additionally, panelists emphasized the importance of addressing historical trauma, the cumulative emotional and psychological wounding over generations resulting from massive group trauma, such as colonization, forced assimilation, and systemic discrimination, and its specific impact on the health of the Native American community.<sup>229</sup>

Integrating a holistic approach and understanding of Native American culture to pediatric care is beneficial to Native American children for two reasons, among others. First, it respects and incorporates their cultural values and practices, which are integral to their identity and well-being.

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<sup>220</sup> Derksen Testimony, 6/29/23 *Web Briefing*, p. 22.

<sup>221</sup> Ibid.

<sup>222</sup> Ibid.

<sup>223</sup> Ibid.

<sup>224</sup> Gordon JS. Holistic medicine: advances and shortcomings. *West J Med.* 1982 Jun;136(6):546-51. PMID: 7113200; PMCID: PMC1273970; <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1273970/>.

<sup>225</sup> Molina Testimony, 3/26/24 *Web Briefing*, pp. 14, 23; Haskon Testimony, 3/26/24 *Web Briefing*, pp. 24-5.

<sup>226</sup> Molina Testimony, 3/26/24 *Web Briefing*, p. 22.

<sup>227</sup> Ibid.

<sup>228</sup> Ibid.

<sup>229</sup> Lovell Testimony, 3/26/24 *Web Briefing*, pp. 16-7, 19; Haskon Testimony, 3/26/24 *Web Briefing*, p. 24; Molina Testimony, 3/26/24 *Web Briefing*, p. 14.



Traditional healing practices, such as the use of medicinal plants, spiritual ceremonies, and the guidance of tribal elders, provide a sense of continuity and cultural heritage that strengthens community bonds and supports mental and emotional health.<sup>230</sup>

Secondly, this approach acknowledges the importance of family and community in shaping children's development.<sup>231</sup> Dr. Molina emphasized the critical role of breaking cycles of learned substance abuse and alcoholism, which in addition to being extremely detrimental to individual health, also perpetuate intergenerational trauma and contribute to the loss of Indigenous culture.<sup>232</sup> By involving families and communities in health initiatives, a holistic approach fosters a supportive environment that promotes healthy behaviors and resilience among children.<sup>233</sup>

In Arizona, where a significant portion of the population identifies as Native American, these issues are particularly relevant. The IHS provides healthcare to many Native American children, but there are still gaps in access and quality of care. For instance, Native American children in Arizona have higher rates of obesity, diabetes, and mental health issues compared to their non-Indigenous peers.<sup>234</sup> They are disproportionately affected by poverty, which exacerbates health disparities.<sup>235</sup> Nearly 40 percent of Native American children live below the federal poverty line, compared to the state average of 18 percent.<sup>236</sup> This economic hardship limits access to healthy foods, safe recreational spaces, and quality healthcare services, all of which are essential for healthy development.<sup>237</sup>

Programs that integrate traditional practices with modern healthcare are showing promise. For example, initiatives that incorporate traditional Navajo healing practices into school-based health

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<sup>230</sup> Buchwald, Dedra & Beals, Janette & Manson, Spero. (2000). Use of Traditional Health Practices Among Native Americans in a Primary Care Setting. *Medical care*. 38. 1191-9. 10.1097/00005650-200012000-00006.

<sup>231</sup> Ibid.

<sup>232</sup> Molina Testimony, 3/26/24 *Web Briefing*, p. 4.

<sup>233</sup> Ibid.

<sup>234</sup> Ibid., p. 5.

<sup>235</sup> Ibid.

<sup>236</sup> Health Resources and Services Administration, *Arizona - 2023 - III.A.1. Program Overview – 2023; “Children in Poverty by Race and Ethnicity” KIDS COUNT Data Center, 2023*, <https://datacenter.aecf.org/data/tables/44-children-in-poverty-by-race-and-ethnicity#detailed/2/4/false/1095,2048,1729,37,871,870,573,869,36,868/187,13/324,323>.

<sup>237</sup> U.S. Department of Health and Human Services, Office of Disease Prevention and Health Promotion, “Poverty - Healthy People 2030,” <https://health.gov/healthypeople/priority-areas/social-determinants-health/literature-summaries/poverty>.

programs have seen success in improving mental health outcomes among children.<sup>238</sup> These programs emphasize the importance of cultural identity and community support, which are vital components of holistic care.<sup>239</sup>

Moreover, community-led health initiatives, such as the Gila River Indian Community's efforts to combat diabetes through culturally relevant education and activities, demonstrate the effectiveness of this holistic approach.<sup>240</sup> By involving elders and leveraging traditional knowledge, these programs foster a sense of belonging and resilience among youth.<sup>241</sup>

Addressing the unique health needs of Native American children in Arizona requires a multi-faceted approach. This can include increasing funding for culturally competent healthcare services, supporting community-led health initiatives, and promoting policies that address social determinants of health, such as poverty and education. Adopting a holistic approach that respects and incorporates Indigenous traditions and knowledge can improve health outcomes and promote healing within these communities.<sup>242</sup>

Furthermore, a holistic approach helps mitigate the impact of historical trauma experienced by many Native American communities. By integrating culturally relevant traditional healing methods, healthcare providers can offer more effective and empathetic care, leading to better health outcomes.<sup>243</sup>

*Finding VII: Bias in treatment of Native American children, raises concern for accessing and receiving quality healthcare.*

Testimony indicated systemic bias in the treatment of Native American children with concerns that it hinders their access to quality healthcare. Alison Lovell, Business Operations Administrator for the Arizona Advisory Council on Indian Health Care, shared personal experiences and anecdotes from teenagers emphasizing the pervasive nature of racial bias and discrimination of

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<sup>238</sup> University of New Mexico, Health Sciences, "An Immersive Journey to Learn Navajo Health Practices," May 31, 2023, <https://hsc.unm.edu/news/2023/05/an-immersive-journey-to-learn-navajo-health-practices.html>; Indian Health Service, "Navajo Wellness Model: Keeping the Cultural Teachings Alive to Improve Health," Newsroom, January 4, 2018, <https://www.ihs.gov/newsroom/ihs-blog/january2018/navajo-wellness-model-keeping-the-cultural-teachings-alive-to-improve-health/>.

<sup>239</sup> Ibid.

<sup>240</sup> Michael Tabasko, "NIH's Work With Native Communities Drives Diabetes Research," National Institutes of Health, The Catalyst, vol. 29, Issue 6., Nov-Dec 2021, <https://irp.nih.gov/catalyst/29/6/nihs-work-with-native-communities-drives-diabetes-research>.

<sup>241</sup> Eschiti, Valerie. (2004). Holistic Approach to Resolving American Indian/Alaska Native Health Care Disparities. Journal of Holistic Nursing: official journal of the American Holistic Nurses' Association. 22. 201-8. 10.1177/0898010104266713.

<sup>242</sup> Ibid.

<sup>243</sup> Molina Testimony, 3/26/24 Web Briefing, p. 5.

healthcare professionals toward Native American teenagers. For instance, she stated that when these teenagers are seen by non-Native American healthcare workers, the immediate questions they were asked dealt with alcohol consumption.<sup>244</sup> On another personal account, she was asked the same questions when she sought treatment for a respiratory infection.<sup>245</sup> These encounters indicate the damaging impact of prejudice on healthcare access and trust, particularly among marginalized populations.

The American Academy of Pediatrics' Committee on Native American Child Health highlighted that

caring for these children presents a unique and complex clinical opportunity ... because of the high level of documented health inequities within a sociocultural context unfamiliar to most practicing providers of pediatric care.<sup>246</sup>

Solutions to addressing systemic bias and trust-building among Native American youth seeking treatment include developing programs and interventions that incorporate Native American and Alaska Native culture, traditions, and practices.<sup>247</sup>

The American Academy of Pediatrics' Committee on Native American Health recommends including Native American and Alaska Native perspectives and disaggregating data in early childhood initiatives, training healthcare staff in culturally sensitive practices,<sup>248</sup> advocating for culturally and linguistically appropriate services,<sup>249</sup> and creating medical homes sensitive to discrimination and unresolved traumas experienced by Native American and Alaska Native families.<sup>250</sup> Additionally, Allison Lovell advocates for representation and cultural sensitivity in healthcare delivery to foster trust and ensure equitable access for children and teenagers as Native American families.<sup>251</sup>

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<sup>244</sup> Lovell Testimony, *3/26/24 Web Briefing*, pp. 9-10.

<sup>245</sup> Ibid.

<sup>246</sup> Shaquita Bell et al., "Caring for American Indian and Alaska Native Children and Adolescents," *Pediatrics* 147, no. 4 (April 1, 2021), <https://doi.org/10.1542/peds.2021-050498>; <https://bit.ly/3VvynRi> (hereafter cited as Shaquita Bell et al., *Caring for American Indian and Alaska Native Children and Adolescents*).

<sup>247</sup> Ibid.

<sup>248</sup> Blue Cross Complete of Michigan. Culturally and Linguistically Appropriate Services (CLAS) provider cultural competency. Available at: <https://www.bcbsm.com/content/dam/microsites/blue-cross-complete/bluecross-complete-clas-trainingpresentation.pdf>. Accessed January 15, 2019.

<sup>249</sup> Shaquita Bell et al., *Caring for American Indian and Alaska Native Children and Adolescents*.

<sup>250</sup> Shaquita Bell et al., *Caring for American Indian and Alaska Native Children and Adolescents*.

<sup>251</sup> Ibid., p. 10.

Gerilene Haskon pointed to cultural insensitivity, language barriers, and financial barriers as factors that exacerbate healthcare disparities among the Native American community.<sup>252</sup> Cultural competency training, implicit bias awareness, and trauma-informed care among healthcare providers are solutions to address these challenges effectively.<sup>253</sup> While generally these elements are especially important for healthcare providers who work within the IHS in building the trust and relationship with the Native American community, these healthcare providers cycle in and out as many typically stay about three to four years (because their service is in exchange for loan forgiveness).<sup>254</sup> The result is that Native American families are sometimes reluctant to take their children or themselves to get care.<sup>255</sup>

Additionally, there are historical trust issues among the Native American community and the Western healthcare system related to data collection. In 2004, the Havasupai Tribe filed a lawsuit against the Arizona Board of Regents and Arizona State University researchers upon discovering that DNA samples, initially collected for genetic studies on type 2 diabetes, had been used in several other genetic studies.<sup>256</sup> This discovery eroded trust, led to profound medical mistrust within the Havasupai Tribe, and continues to complicate trust-building efforts between healthcare providers and Native American patients.<sup>257</sup>

Dr. Page presented data from 2019 showing disparities in the diagnosis and intervention for Arizona children with hearing loss, revealing that Native American children were more likely to experience delays in diagnosis, with 43 percent experiencing delays compared to 25 percent of non-Native children, and that children from households with lower maternal education were 30 percent less likely to receive timely interventions.<sup>258</sup>

Dr. Feldstein proposed revising Arizona Statute 32-1421 to allow practitioners certified by accredited professional boards to practice within their scope, highlighting the fact that medicine men on tribal reservations are already exempted.<sup>259</sup> Additional testimonies from Drs. Felman and Derksen acknowledged implicit biases in healthcare and the need for more research in this area.<sup>260</sup>

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<sup>252</sup> Haskon Testimony, *3/26/24 Web Briefing*, p. 12.

<sup>253</sup> Molina Testimony, *3/26/24 Web Briefing*, pp. 11-2; 14-5.

<sup>254</sup> Haskon Testimony, *3/26/24 Web Briefing*, p. 12.

<sup>255</sup> *Ibid.*

<sup>256</sup> *Havasupai Tribe v. Arizona Board of Regents*, 220 Ariz. 214 (Ariz. Ct. App. 2009).

<sup>257</sup> Nanibaa' A. Garrison, "Genomic Justice for Native Americans," *Science, Technology, & Human Values* 38, no. 2 (December 2012): 201–23, <https://doi.org/10.1177/0162243912470009>; Lovell Testimony, *3/26/24 Web Briefing*, p. 15.

<sup>258</sup> Page Testimony, *9/26/23 Web Briefing*, p. 20; Presentation slide 71.

<sup>259</sup> Feldstein Testimony, *9/26/23 Web Briefing*, pp. 24-5.

<sup>260</sup> *Ibid.*, p. 29; Derksen Testimony, *6/14/23 Web Briefing*, p. 30.

Dr. Felman suggested funding screening tools for racism and considering self-identification markers to reduce biases.<sup>261</sup> She also shared anecdotal evidence of patients from different cultural backgrounds not feeling heard or understood by healthcare providers and pointed to the policy statement from the American Academy of Pediatrics addressing racism in healthcare which includes recommendations for consideration.<sup>262</sup> Dr. Derksen highlighted the importance of diversity within the healthcare workforce and representation, citing success stories of healthcare professionals from minority communities serving as role models.<sup>263</sup> For example, having Native American healthcare professionals can improve patient trust and adherence to medical advice, resulting in better health outcomes.<sup>264</sup>

Amanda Hagerman, Policy Analyst at the Goldwater Institute, suggested exploring qualitative data from state or county health departments to understand healthcare perceptions among minority populations.<sup>265</sup> For instance, surveys conducted in Arizona revealed that 65 percent of Native American respondents reported experiencing discrimination in healthcare settings.<sup>266</sup> This likely has a deterrent effect on Native Americans seeking treatment.<sup>267</sup>

*Finding VIII: Underfunding of healthcare access in Native American communities raises civil concerns due to the federal government's responsibility in providing healthcare services.*

The underfunding of healthcare access in Native American communities is a pressing concern due to the federal government's responsibility to provide healthcare services. The IHS, tasked with that responsibility, has historically been underfunded and unable to meet the needs of the population it serves.<sup>268</sup> This results in inadequate care for many Native American families and children.<sup>269</sup> The IHS, which has been providing tribal healthcare since the 1800s under treaty

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<sup>261</sup> Felman Testimony, 6/14/23 Web Briefing, pp. 16-7.

<sup>262</sup> Ibid., p. 29; American Academy of Pediatrics, *The Impact of Racism on Child and Adolescent Health*.

<sup>263</sup> Derksen Testimony, 6/14/23 Web Briefing, p. 30.

<sup>264</sup> Ibid; Lewis ME, Wildcat S, Anderson A. Visioning an Effective Health Encounter: Indigenous Healthcare Experiences and Recommendations for Health Professionals. *Int J Environ Res Public Health*. 2023 Oct 13;20(20):6917. doi: 10.3390/ijerph20206917. PMID: 37887655; PMCID: PMC10606678; Daniel Bal, "How Nurses Can Build Better Trust With American Indian Patients | NurseJournal.org," NurseJournal.org, August 29, 2022, <https://nursejournal.org/resources/how-nurses-can-build-better-trust-with-american-indian-patients/>.

<sup>265</sup> Hagerman Testimony, 6/14/23 Web Briefing, pp. 30-1.

<sup>266</sup> Findling MG, Casey LS, Fryberg SA, Hafner S, Blendon RJ, Benson JM, Sayde JM, Miller C. Discrimination in the United States: Experiences of Native Americans. *Health Serv Res*. 2019 Dec;54 Suppl 2(Suppl 2):1431-1441. doi: 10.1111/1475-6773.13224. Epub 2019 Oct 27. PMID: 31657013; PMCID: PMC6864378.

<sup>267</sup> Molina Testimony, 3/26/24 Web Briefing, pp. 14-5; Haskon Testimony, 3/26/24 Web Briefing, p. 12; Lovell Testimony, 3/26/24 Web Briefing, pp. 9-10.

<sup>268</sup> U.S. Commission on Civil Rights, *A Quiet Crisis: Federal Funding and Unmet Needs in Indian Country*, Jul. 2003, <https://www.usccr.gov/files/pubs/na0703/na0204.pdf>.

<sup>269</sup> Ibid.

obligations, operates facilities that are frequently inadequate and understaffed.<sup>270</sup> This chronic underfunding was a significant issue raised by the San Carlos Apache Tribe in Arizona in the cases of *Becerra v. San Carlos Apache Tribe* and *Becerra v. Northern Arapaho Tribe*.<sup>271</sup> Both Tribal Nations sued to ensure full contract support cost reimbursement from the IHS for the direct healthcare services provided on their reservations.<sup>272</sup> On June 6, 2024, the U.S. Supreme Court affirmed that the 1975 Indian Self-Determination Act (ISDA) requires the IHS to reimburse Tribal Nations that manage the administration and operation of healthcare programs for their expenditures from revenues collected from third-party payors like Medicare, Medicaid, and private insurers.<sup>273</sup>

This decision is particularly relevant to children in Arizona. First, health disparities are a significant concern. Many Native American children in Arizona rely on the IHS for their healthcare needs.<sup>274</sup> The chronic underfunding and resource shortages in IHS facilities directly affect these children's access to necessary medical care.<sup>275</sup> Consequently, this can lead to untreated illnesses, inadequate preventive care, and overall poorer health outcomes compared to non-Native American children.<sup>276</sup>

Secondly, health is intrinsically linked to education and overall well-being.<sup>277</sup> Poor health due to inadequate healthcare services can result in higher absenteeism,<sup>278</sup> lower academic

<sup>270</sup> Ibid.

<sup>271</sup> *Becerra v. San Carlos Apache Tribe*, 602 U.S. 222 (2024).

<sup>272</sup> *Id.*

<sup>273</sup> *Becerra, et al. v. San Carlos Apache Tribe*. 620 U.S. 222 (2024); Lindsay Whitehurst, "Supreme Court Sides With Native American Tribes in Health Care Funding Dispute | AP News," AP News, June 6, 2024, <https://apnews.com/article/native-american-tribes-healthcare-indian-health-service-2b13ca21d150ab3ee1d85c966f387d54>; Native American Rights Fund, "Supreme Court Affirms Federal Support for Tribal Healthcare Must Be on Equal Footing With IHS Programs - Native American Rights Fund," June 10, 2024, <https://narf.org/becerra-amicus/>.

<sup>274</sup> Lovell Testimony, *3/26/24 Web Briefing*, p. 7.

<sup>275</sup> Warne D, Frizzell LB. American Indian health policy: historical trends and contemporary issues. *Am J Public Health*. 2014 Jun;104 Suppl 3(Suppl 3):S263-7. doi: 10.2105/AJPH.2013.301682. Epub 2014 Apr 22. PMID: 24754649; PMCID: PMC4035886.

<sup>276</sup> Ibid.

<sup>277</sup> Zajacova A, Lawrence EM. The Relationship Between Education and Health: Reducing Disparities Through a Contextual Approach. *Annu Rev Public Health*. 2018 Apr 1;39:273-289. doi: 10.1146/annurev-publhealth-031816-044628. Epub 2018 Jan 12. PMID: 29328865; PMCID: PMC5880718.

<sup>278</sup> "Fourth Graders Who Are Chronically Absent From School by Race and Ethnicity | KIDS COUNT Data Center," n.d., <https://datacenter.aecf.org/data/line/8817-fourth-graders-who-are-chronically-absent-from-school-by-race-and-ethnicity?loc=1&loct=1#1/1/false/1095,1729,871,573,36,867,38,18,16,14/asc/13/17671> (In 2022, about half (49%) of AI/AN fourth-grade students were considered chronically absent from school in the previous month, an alarming jump from 31% in 2019, and well above the national average of 36% in 2022); The Annie E. Casey Foundation,

performance,<sup>279</sup> and increased dropout rates among Native American children in Arizona.<sup>280</sup> This not only hampers their educational attainment but also perpetuates cycles of poverty and limits future opportunities for these children.

Moreover, mental health services, which are crucial for addressing conditions such as depression, anxiety, and trauma, are also affected by the lack of funding for IHS.<sup>281</sup> Native American children in Arizona may face higher rates of these mental health conditions due to historical and ongoing socio-economic challenges.<sup>282</sup> Inadequate mental health support exacerbates these issues, leading to long-term negative impacts on their mental well-being.<sup>283</sup>

The legal and social advocacy demonstrated in the cases of *Becerra v. San Carlos Apache Tribe*<sup>284</sup> calls attention to the importance of securing the rights and resources necessary for Native

“Chronic Absenteeism in U.S. Schools Rose During Pandemic — and Hasn’t Recovered,” September 20, 2023, <https://www.aecf.org/blog/chronic-absenteeism-in-u-s-schools-rose-during-pandemic-and-hasnt-recovered>. (AI/AN fourth graders have been more likely than their peers in other racial or ethnic groups to experience chronic absenteeism, which can include excused absences due to health issues, transportation problems or other barriers).

<sup>279</sup> “Fourth Graders Who Scored Below Proficient Reading Level by Race and Ethnicity | KIDS COUNT Data Center,” n.d., <https://datacenter.aecf.org/data/bar/5126-fourth-graders-who-scored-below-proficient-reading-level-by-race-and-ethnicity?loc=1&loct=1#1/any/false/1095/10,168,9,12,185,107/11557>, (In 2022, more than 8 in 10 (82%) AI/AN fourth-grade students scored below proficient in reading, an increase from previous years and a higher share than the national average (68%).); “Eighth Graders Who Scored Below Proficient Math Achievement Level by Race and Ethnicity | KIDS COUNT Data Center,” <https://datacenter.aecf.org/data/bar/7665-eighth-graders-who-scored-below-proficient-math-achievement-level-by-race-and-ethnicity?loc=1&loct=1#1/any/false/1095/107,9,12,168,10,185/14819>; “Eighth Graders Who Scored Below Proficient Math Achievement Level by Race and Ethnicity | KIDS COUNT Data Center,” <https://datacenter.aecf.org/data/bar/7665-eighth-graders-who-scored-below-proficient-math-achievement-level-by-race-and-ethnicity?loc=1&loct=1#1/any/false/1095/107,9,12,168,10,185/14819>, (About 9 in 10 (89%) AI/AN eighth-grade students scored below proficient in math in 2022, 10 percentage points higher than a decade earlier and 15 percentage points above the national average of 74%. Math proficiency in eighth grade and reading proficiency in fourth grade are bell-wether indicators of long-term academic success — including graduating from high school, which increases employment and earning potential in adulthood.

<sup>280</sup> “High School Students Not Graduating on Time by Race and Ethnicity | KIDS COUNT Data Center,” n.d., <https://datacenter.aecf.org/data/bar/9538-high-school-students-not-graduating-on-time-by-race-and-ethnicity?loc=1&loct=1#1/any/false/1769/725,4041,12,1,185,13/18713>, (One in 4 (25%) AI/AN high school students is not graduating on time. This is higher than the national rate (14%) and that of all other racial and ethnic groups with data, according to 2019–2020 data.)

<sup>281</sup> United States Government Accountability Office, “Report to the Committee on Indian Affairs, U.S. Senate: Actions Needed to Improve Oversight of Patient Wait Times,” March 2016, <https://www.gao.gov/assets/gao-16-333.pdf>; O’Keefe VM, Cwik MF, Haroz EE, Barlow A. Increasing culturally responsive care and mental health equity with indigenous community mental health workers. *Psychol Serv.* 2021 Feb;18(1):84-92. doi: 10.1037/ser0000358. Epub 2019 May 2. PMID: 31045405; PMCID: PMC6824928.

<sup>282</sup> Kwon SC, Kabir R, Saadabadi A. Mental Health Challenges in Caring for American Indians and Alaska Natives. [Updated 2024 Feb 12]. In: StatPearls [Internet]. Treasure Island (FL): StatPearls Publishing, <https://www.ncbi.nlm.nih.gov/books/NBK570587/>.

<sup>283</sup> Ibid.

<sup>284</sup> *Becerra v. San Carlos Apache Tribe*, 602 U.S. 222 (2024).

American communities. The Supreme Court's decision reinforces the federal government's obligations under the ISDA, setting a precedent that can lead to improved funding and support for health services.<sup>285</sup> Native American groups consider this ruling is a critical step towards addressing systemic healthcare inequities faced by Native American children in Arizona.<sup>286</sup>

Additionally, ensuring adequate healthcare funding and support empowers tribal communities to exercise greater control over their health services.<sup>287</sup> This empowerment can lead to culturally appropriate and effective health interventions, promoting better health outcomes for Native American children.<sup>288</sup> Community-driven health programs are more likely to understand and address the unique health challenges and cultural contexts of Native American populations.<sup>289</sup>

Looking ahead, the decision to uphold full contract support cost reimbursement could lead to increased resources and better healthcare infrastructure for the IHS and tribal health programs.<sup>290</sup> Over time, this can result in improved health services and outcomes for Native American children in Arizona, fostering healthier communities and reducing health disparities.<sup>291</sup>

## Recommendations

Among their duties, advisory committees of the Commission are authorized to advise the Agency (1) concerning matters related to discrimination or a denial of equal protection of the laws under the Constitution and the effect of the laws and policies of the Federal Government with respect to equal protection of the laws, and (2) upon matters of mutual concern in the preparation of reports of the Commission to the President and the Congress.<sup>292</sup> Recommendations are specific actions or proposed policy interventions intended to address or alleviate the civil rights concerns raised in

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<sup>285</sup> Levi Rickert, "Supreme Court Backs Tribes in Healthcare Funding Dispute," Native News Online, Jun. 7, 2024, <https://nativenewsonline.net/health/us-supreme-court-rules-in-favor-of-tribes-to-receive-healthcare-administration-costs-reimbursement> (hereafter cited as Native News Online, *Supreme Court Backs Tribes in Healthcare Funding Dispute*).

<sup>286</sup> Native News Online, *Supreme Court Backs Tribes in Healthcare Funding Dispute*.

<sup>287</sup> "NCUIH Calls for Full, Protected Funding of Indian Health Service & Funding for Key Indian Health Programs in Written Testimony to House and Senate Appropriators," NCUIH, Jun. 24, 2024, <https://ncuih.org/2024/06/24/ncuih-calls-for-full-protected-funding-of-indian-health-service-funding-for-key-indian-health-programs-in-written-testimony-to-house-and-senate-appropriators/>.

<sup>288</sup> Ibid.

<sup>289</sup> Shaquita Bell et al., *Caring for American Indian and Alaska Native Children and Adolescents*.

<sup>290</sup> Native News Online, *Supreme Court Backs Tribes in Healthcare Funding Dispute*.

<sup>291</sup> Native News Online, *Supreme Court Backs Tribes in Healthcare Funding Dispute*.

<sup>292</sup> 45 C.F.R. § 703.2.



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the related finding(s). In keeping with these responsibilities, and given the testimony heard on this topic, the Committee submits the following recommendations to the Commission:

1. The U.S. Commission on Civil Rights should send this report and issue the following recommendations to the U.S. Department of Health and Human Services, Centers for Medicare and Medicaid Services:
  - a. Approve the state's request to amend Section 1115 of the Social Security Act that would provide multiyear continuing enrollment to former foster youth who have aged out of foster care at age 18 and up to age 26.
2. The U.S. Commission on Civil Rights should send this report and issue the following recommendations to the U.S. Congress:
  - a. Lift the cap on Medicare-funded residency positions as it would enhance access to care and help medical facilities meet the needs of the communities they serve, allow hospitals more flexibility to diversify and maintain training programs, and train residents in more diverse facility types such as smaller rural hospitals which may not be able to operate their own training programs.
  - b. Increase funding for the National Health Services Loan Repayment program and the Conrad 30 waiver program to incentivize healthcare professionals to work in underserved areas.
3. The U.S. Commission on Civil Rights should send this report and issue the following recommendations to the Arizona Legislature:
  - a. Mandate that the parents of all children born in the state receive, at the time of birth, written notification of the eligibility criteria for health insurance provided by the Arizona Health Care Cost Containment System, including Arizona's Children's Health Insurance Program (also known as KidsCare), and instructions for how and by when to enroll in the program and renew coverage. Additionally, require that the state provide notification to renew coverage every year after until age 26.
  - b. Increase funding for outreach and awareness regarding the newly enacted KidsCare program to ensure families know how to enroll.
  - c. Increase funding of the Young Adult Transitional Insurance program to ensure that former foster youth continue their health insurance.

- d. Research and recommend ways to increase access to affordable medical education.
  - e. Research and recommend ways to increase access to medical professionals throughout the state and especially in rural communities.
4. The U.S. Commission on Civil Rights should send this report and issue the following recommendations to the Arizona Governor:
    - a. Emphasize the importance of improving and increasing access to pediatric healthcare for children from racial and ethnic minority communities.
    - b. Communicate with state agencies to develop initiatives to advance access to pediatric healthcare for racial and ethnic minority communities.
  5. The U.S. Commission on Civil Rights should send this report and issue the following recommendations to the Arizona Department of Health Services:
    - a. Increase education and outreach regarding the expanded eligibility for low-income children to access KidsCare.
    - b. Ensure programs are culturally responsive to the specific needs of underserved communities.
    - c. Assist in funding KidsCare to the extent it will increase access to pediatric healthcare for racial and ethnic minorities in Arizona.

Additionally, the Committee requests the U.S. Commission on Civil Rights to send this report to the U.S. Department of Health and Human Services and the U.S. Department of Health and Human Services, Indian Health Service for review.

**Link to relevant report materials:**

<https://usccr.box.com/s/dwf31qhnjgsevgydf9ctfbz1y89w6z3r>

## Appendix

### List of Invited Panelists

#### Briefing I on June 14, 2023

- Dr. Daniel Derksen, Professor of Public Health, Medicine & Nursing, Associate Vice President for Health Equity, Outreach & Interprofessional Activities, University of Arizona
- Amanda Hagerman, MPH, Policy Analyst, Goldwater Institute
- Dr. Helene Felman, Division Chief of General Pediatrics, Clinical Associate Professor of Pediatrics, Advocacy Director of the Pediatric Residency Program, Banner – University Medical Center/ University of Arizona Tucson

#### Briefing II on September 29, 2023

- Matt Jewett, Director of Health Policy, Children’s Action Alliance
- Dr. Murray Feldstein, Visiting Fellow, Goldwater Institute
- Dr. Nathan Page, Pediatric Otolaryngologist, Phoenix Children’s Hospital

#### Briefing III on February 2, 2024

- Dr. Darlene Melk, Chief Medical Officer, Chiricahua Community Health Centers, Inc.

#### Briefing IV on March 26, 2024

- Dr. John Molina, Director, Arizona Advisory Council on Indian Health Care
- Alison Lovell, Business Operations Administrator, Arizona Advisory Council on Indian Health Care
- Gerilene Haskon, Tribal Liaison, Arizona Department of Health Services

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## Arizona Advisory Committee to the United States Commission on Civil Rights



### U.S. Commission on Civil Rights

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