UnitedHealthcare Community & State
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Health Equity in Medicaid Report:

Challenges & Opportunities

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United
Healthcare

Executive Summary

Health starts in our homes, schools, workplaces, and communities. When there are individual, provider, societal, and environmental challenges present, new and longstanding disparities multiply and widen. Significant work must be done to reduce disparities and create equity, the drive to achieve fairness in outcomes given one's unique needs and differing opportunities or access to resources.

COVID-19 brought many deeply rooted health equity issues to light. The COVID-19 pandemic has disproportionately affected underserved groups, including Black, Indigenous, and people of color (BIPOC), rural, and socioeconomically disadvantaged populations, resulting in higher rates of infection, hospitalization, and death. This trend has continued throughout the pandemic – even with the targeted efforts to reduce COVID-19 disparities, they persist. It is a stark reminder of the complexities, challenges, and opportunities we face as a society.

Without action and information, disparities will continue to multiply and widen. To advance toward equity, we must be inclusive and intentional in our efforts, and we must create common goals, language, and understanding.

At UnitedHealthcare, we are committed to making the health care system work better for everyone. As part of this commitment, we must address the disparities that prevent people from living their healthiest lives. Regardless of race, gender, sexual orientation, gender identity, geography, disability status, and all other demographic factors, the communities and individuals we serve deserve the opportunity and access necessary to achieve their optimal health and wellness.

To that end, UnitedHealthcare Community & State created the 2022 Report on Health Equity in Medicaid. This resource details how the topic of health equity is permeating nearly all national and state level Medicaid-related conversations.

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Part 1: Health Equity 101

Definitions/Terms

To effectively make progress toward reducing disparities and inequities, those involved must align on common goals by using shared, well-defined terminology. Health equity cannot be achieved without consensus around common definitions. Varying definitions can create additional divides that hinder equity efforts and engagement. To foster alignment prior to delving into health equity, several common definitions are presented below.

- **Health Equity:** Health equity means everyone has a fair and just opportunity to achieve their full health potential and be as healthy as possible. This requires reducing obstacles such as poverty, discrimination, and their consequences, including powerlessness and lack of access to good jobs with fair pay, quality education and housing, and health care.[1] Equity is not the same as equality. Equality means everyone must receive the same resources, regardless of their unique needs and circumstances. Equity considers the unique needs and circumstances of individuals and allows resources to cater to those needs to reach an equal outcome.
- **Health Disparities:** Avoidable differences in health status that can be linked to social, economic, and/or environmental disadvantages.[2]
- **Health Inequities:** Differences that are unfair and unjust without comparison to another group (e.g., inequitable access to transportation means there is an unjust lack of transportation for the population being discussed; a disparity in access to transportation means that one group has less access than another).[3]
- **Systemic Racism:** A complex system, rooted in historical and current realities of differential access to power and opportunity for different racial groups. This system is embedded within and across laws, structures, and institutions in a society or organization. This includes laws, inherited disadvantages (e.g., the intergenerational impact of trauma) and advantages (e.g., intergenerational transfers of wealth), and standards and norms rooted in racism.[4]
- **Social Risk Factors:** Commonly referred to as the social determinants of health (SDOH), social risk factors are adverse social, economic, and environmental conditions that lead to poor health outcomes. It is estimated that approximately 80% of health outcomes are impacted by these social drivers[5], including housing, nutrition, transportation, employment, and interpersonal violence.

Health Disparities and Inequities – Causes and Impact

Health disparities and inequities can be based on several factors including but not limited to:

- Race
- Ethnicity
- Language
- Sexual Orientation
- Disability Status
- Gender Identity
- Income
- Education
- Geography
- Age
- Social Risk Factors

To put disparities and inequities into context, it is helpful to examine health measures with widespread disparities. According to America's Health Rankings:[6]

- **Uninsured rate:** Over the last decade, the national uninsured rate declined 37%, from 14.6% to 9.2%, with all subpopulation groups experiencing improvements. Despite this progress, gaps remained between different population groups. For example, from 2015-2019, the uninsured rate was 3.5 times higher for those with only a high school degree (13.6%) than for college graduates (3.9%) and roughly 3 times higher among Hispanic (18.5%) and American Indian/Alaska Native populations (20.2%) than white populations (6.2%).

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[1] Robert Wood Johnson Foundation
[2] Robert Wood Johnson Foundation
[3] State Health & Value Strategies
[4] State Health & Value Strategies
[5] Robert Wood Johnson Foundation
[6] America's Health Rankings

- **Infant Mortality:** From 2015-2018, Black infants had the highest infant mortality rate (11.0 per 1,000 births) — which was 2.8 times higher than Asian/Pacific Islander infants (4.0 per 1,000 births).
- **Maternal Morality:** From 2015-2019, Black mothers had a maternal mortality rate (43.8 deaths per 100,000 live births) that was 3.4 times higher than Hispanic mothers (12.7 deaths per 100,000 live births). Between 2005-2009 and 2015-2019, maternal mortality rates increased 22% among Black mothers (from 35.8 to 43.8 deaths per 100,000 live births) and 23% for Hispanic mothers (from 10.3 to 12.7 deaths per 100,000 live births).
- **Mental Health:** From 2017-2019, adults with less than a high school education had a rate of frequent mental distress (17.6%) that was 123% higher than college graduates (7.9%). Females (23.9%) had a 70% higher rate of depression compared to males (14.1%). Mental health challenges were more prevalent among some racial and ethnic groups. For example, the rate of depression was three times higher for multiracial (27.1%) and American Indian/Alaska Native adults (24.6%) and 2.5 times higher for white adults (21.1%) than Asian/Pacific Islander adults (8.6%). Despite performing better than other groups, Asian/Pacific Islander adults experienced the highest increase (23%) in the rate of depression from 7.0% in 2011-2013 to 8.6% in 2017-2019. There are also significant mental health disparities among LGBTQ+ populations, especially young people, who are more than four times as likely to attempt suicide as their peers. The rate is even higher for non-white youth who report being LGBTQ+.[7]

4x

LGBTQ+ youth are more than 4x as likely to attempt suicide as their peers, a rate that is even more significant for racial and ethnic minority youth who report being LGBTQ+.

In addition, social risk factors disproportionately impact underserved populations that have downstream negative impacts on health outcomes.

- **Food Insecurity:** Even prior to the COVID-19 pandemic, disparities in household food insecurity — the percentage of households unable to provide adequate food for one or more household members due to lack of resources — were wide. The gaps widened further between 2003-2007 and 2015-2019, when food insecurity rates increased 39% for American Indian/Alaska Native households (from 19.2% to 26.7%) — a rate five times higher than experienced by Asian/Pacific Islander (5.6%) households. Disparities in food insecurity were also significant across levels of education. From 2015-2019, households headed by an adult without a high school education (24.8%) had rates of food insecurity nearly six times higher than households headed by college graduates (4.4%).
- **Severe Housing Problems:** Despite progress in reducing the percentage of households facing severe housing problems, households headed by Hispanic (29.9%), Black (25.3%), and American Indian/Alaska Native (24.2%) individuals had a rate of severe housing problems roughly two times higher than households headed by white (13.4%) individuals. Housing and homelessness significantly impact LGBTQ+ youth, who are more than twice as likely to experience homelessness than their non-LGBTQ+ peers. Non-white LGBTQ+ youth reported the highest rates of homelessness (16%), while white LGBTQ+ youth reported a rate of 8%.[8]

2x

Households headed by Hispanic, Black, and American Indian/Alaska Native individuals had a rate of severe housing problems nearly 2x higher than households headed by white individuals.

Individuals living with disabilities also experience significant access barriers that result in health disparities.[9] These include but are not limited to:

- **Transportation:** Individuals with functional disabilities are more likely to experience transportation barriers due to costs, distance, availability, and accessibility. Even when accessible transportation is available, the time required to travel to providers is significant and can have negative impacts on health.

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[7] The Trevor Project

[8] Youth.gov

[9] UnitedHealthcare Community & State

- **Facility and Treatment Challenges:** Many health care facilities and locations are not fully accessible to individuals with functional disabilities. In addition, many diagnostic tests result in light and noise that can trigger sensory issues. These barriers often prevent individuals with disabilities from seeking care.
- **Communications Challenges:** Accessing medical information and understanding policies are often difficult, but this is further compounded with the lack of disability etiquette present in many health care facilities.

COVID-19

The COVID-19 pandemic has disproportionately affected underserved groups of society, including BIPOC, rural, and socioeconomically disadvantaged populations, resulting in higher rates of infection, hospitalization, and death. This trend has continued throughout the pandemic – even with the targeted efforts to reduce COVID-19 disparities, they persist.

Average weekly rate, per 100,000 (December 2021-February 2022)

	Black Americans	White Americans
Cases	326.2	269.7
Hospitalizations	27.1	14.6
Deaths	2.1	1.7

Sources: Center for Disease Control and Prevention: COVID Data Tracker & COVID-19 Associated Hospitalization Surveillance Network

Figure 1: Impact of COVID-19

There are many elements that contribute to why COVID-19 has had greater impacts on BIPOC communities, including:

- **Occupation:** Social distancing is a useful prevention measure to inhibit the spread of COVID-19, but for some communities adequate social distancing is not possible. When many employers shifted to work-from-home practices, “essential workers” in the health care, food, or service industries reported to work, leading to often greater exposure and higher spread given the dynamics of their working environments. Additionally, given the work hours and lack of benefits typically associated with these occupations, essential workers often delay accessing treatment due to a lack of paid time off or fear of losing their job. BIPOC make up a roughly half of the population of essential workers in the U.S.[10]
- **Housing:** Higher percentages of BIPOC communities live in multigenerational households[11], with many underserved individuals also experiencing crowded living conditions. Both factors can lead to increased risk of transmission and hinder disease prevention strategies.
- **Access:** Health care costs and the lack of insurance often create a barrier for underserved groups to seek care and treatment. Additionally, non-white groups are often provided with lower quality care than their white counterparts.[12] Delaying care can exacerbate conditions and put individuals at a higher risk of serious and/or fatal effects.

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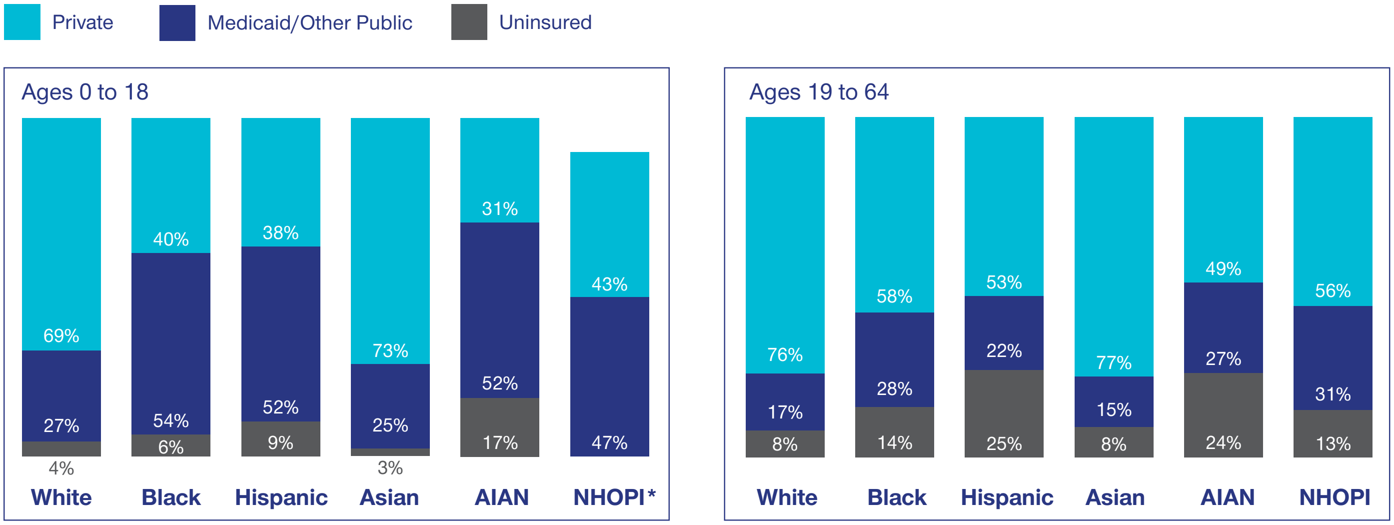
[10] Nearly Half of COVID-19 Essential Workers are BIPOC | Well+Good (wellandgood.com)
[11] Fighting Poverty in a Tough Economy, Americans Move in with Their Relatives
[12] Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care |The National Academies Press

Medicaid Impact

Compared to commercial and employer-based insurances, Medicaid covers a high proportion of underserved groups, meaning Medicaid beneficiaries are more likely to be impacted by health disparities. This has incentivized both the federal government and state Medicaid programs to place an emphasis on promoting health equity and reducing health disparities. States are increasingly leveraging Medicaid managed care to target population health needs, address health related social needs, and reduce health disparities for their Medicaid populations.

Medicaid provides health care coverage to over 82 million individuals as of June 2022.[13] As shown here, Medicaid covers higher percentages of individuals who identify as non-white. As of 2020, Medicaid covers about three in ten Black, American Indian/Alaska Native, and Native Hawaiian or Other Pacific Islander nonelderly adults and more than two in ten Hispanic nonelderly adults, compared to 17% of their white counterparts.

Health Coverage of Non-elderly Population by Race and Ethnicity, 2020



NOTE: Persons of Hispanic origin may be of any race but are categorized as Hispanic for this analysis; other groups are non-Hispanic. AIAN refers to American Indian and Alaska Native people. NHOPI refers to Native Hawaiian and Other Pacific Islander people. Other public coverage includes Medicare (excluding Part A only) and military coverage. Totals may not sum to 100 percent due to rounding. *Uninsured rate for NHOPI children is not reported because it has a relative standard error above 30%.

SOURCE: KFF estimates based on the Census Bureau's March Current Population Survey (CPS: Annual Social and Economic Supplements), 2021

State Activity

With the severity of health disparities, especially for Medicaid populations, coming into greater focus, states are increasingly considering and implementing a variety of tools that will help them and their MCO partners to reduce these disparities most effectively. In the most recent Kaiser Family Foundation Annual Medicaid Budget Survey (KFF Survey)[15], states were asked to highlight specific strategies they were deploying in service to identifying and addressing health disparities and advancing health equity in their Medicaid programs. These strategies include:

- **Agency Structure:** A number of states identified establishing health equity-related committees, advisory councils, or task forces to support the development and execution of strategies focused on addressing health inequities in their Medicaid population.
- **Data Collection:** Majority of states are using at least one specific strategy to improve REL data completeness. Efforts range from modifying agency materials to better explain how REL data will be used and/or why providing the data is important to finding ways to leverage or link to other data sources to obtain additional REL data to requiring MCOs to collect REL data.

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[13] June 2022 Medicaid & CHIP Enrollment Data Highlights | Medicaid

[14] Kaiser Family Foundation

[15] How the Pandemic Continues to Shape Medicaid Priorities: Results from an Annual Medicaid Budget Survey for State Fiscal Years 2022 and 2023 – Health Equity – 10030 | KFF

- **Quality Incentives:** A quarter of states use financial incentives to improve quality by linking performance bonuses or penalties, capitation withholds, or value-based payment to quality measures. In most instances, these incentives are within managed care arrangements, but a handful of states are implementing similar incentives in their fee-for-service systems.
- **Performance Improvement Plans (PIPs):** Half of responding states to the KFF Survey reported requiring MCOs to participate in PIPs focused on health disparities.
- **MCO Contracts:** States are leveraging managed care contracts to promote their health equity-related goals. New contractual requirements are focused on elements such as staff training on health equity and/or implicit bias, new staff roles related to health equity, requiring MCOs to have a health equity plan, and achievement of national standards for culturally competent care (i.e., NCQA's Distinction in Multicultural Health Care).

Federal Activity

Like states, the Centers for Medicare and Medicaid Services (CMS) is also working to advance health equity and reduce disparities for Medicaid populations. On April 20, 2022, CMS outlined an action plan designed to enhance the health equity focus embedded in the full range of programs administered by CMS.[16] Among the overarching goals included in the plan are efforts to:

- Close gaps in health care access, quality, and outcomes;
- Build on outreach efforts in Medicaid and Children's Health Insurance Program;
- Expand and standardize the collection of race, ethnicity, and gender identity data across CMS programs;
- Incorporate additional screening for health-related social needs; and,
- Promote quality outcomes and safe care for all beneficiaries of CMS programs.

In keeping with direction from the Biden administration, CMS has established health equity as the first pillar of its larger fiscal year 2022-2026 strategic plan. CMS intends to convene industry stakeholders, including health care facilities, insurance companies, state officials, and providers in support of the equity action plan.

Other notable federal efforts to advance equity include:

- **Value-Based Payment:** CMS continues to look for ways to use value-based payment models to reduce health disparities across patient groups and assess equity achievements at the provider level.[18]
- **COVID-19 Task Force:** President Biden established the COVID-19 health equity task force to address the disproportionate impact of COVID-19 on underserved communities through several initiatives, including improving data collection, investing in a representative health care workforce, and ensuring equitable access to COVID-19 tests, therapies, and vaccines.[19]
- **Maternal Health Initiatives:** Acknowledging that Black and Native American/Alaska Native women have higher rates of maternal mortality, the Department of Health and Human Services (HHS) invested $350 million to support safe pregnancies and births.[20] In addition, HHS continues to work to expand access to high-quality maternal care nationwide.[21]

Opportunities for the Medicaid Program

Even with the increased activity by states and the federal government, there remain significant opportunities to reduce health disparities and achieve health equity.

- **Data:** Improving the collection and accuracy of race and ethnicity data will better allow for the assessment of trends in quality of care and drive provider accountability for addressing health disparities. Collecting this data consistently and accurately is a necessary precursor to moving to stratified performance and outcome measurement.
- **Programmatic Focus:** By leveraging a strategic planning or strategic framework, states can provide clarity and a roadmap to all stakeholders that outlines the actions and philosophy for addressing health equity within the context of the program's

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[16] Centers for Medicare and Medicaid Services (CMS)
[17] Department of Health and Human Services
[18] Modern Healthcare
[19] Department of Health and Human Services
[20] Department of Health and Human Services
[21] Department of Health and Human Services

existing structure, priorities, and resources. Finding ways to infuse health equity into existing practices – reporting, performance improvement plans, continuous quality improvement, procurements, etc. – allows for an efficient use of limited state resources while also ensuring a holistic, integrated approach to improving health outcomes equitably. It also helps to identify inadvertent practices within program design or operations that may be contributing to disparities.

- **Training:** Continued education and conversations regarding health equity, including on racial, ethnic, disability, gender, sexual orientation, and geographic disparities that exist in the Medicaid population for providers, MCOs, community-based organizations, and state leaders is a critical first step to engaging collectively to address these disparities.
- **Culturally Aligned Programs:** States should develop benefit and program designs that ensure access to services and supports that are culturally aligned with the needs of members and that help decrease barriers to accessing care. For example, some states are requesting coverage of traditional healing services provided by Indian Health Services and tribal facilities to support access to this service for their American Indian and Alaska Native beneficiaries.
- **Value-Based Payment:** By embedding mechanisms to improve health equity in value-based payment models, states and MCOs can incentivize providers to invest in delivery system transformations that can reduce health disparities and drive health equity. To do this, trust in the data and established programmatic alignment with state priorities must be in place.

Part 2: Health Equity & The Role of Data

Data are at the foundation of meaningfully improving health outcomes. Data help identify health disparities, inform tailored interventions to reduce those disparities, evaluate those interventions to ensure meaningful progress, and track the advancement of health equity. To be useful, data must be consistent, granular, complete, and accurate. Without adequate and credible data, the full extent of inequities across the system remains hidden and any efforts to advance health equity are inhibited.

The demographic data considered most beneficial when working to advance health equity vary, but often include the following:

- Race
- Ethnicity
- Language
- Sexual Orientation
- Gender Identity
- Disability Status
- Geography

Collecting comprehensive demographic data is an essential step toward identifying and reducing health disparities. Demographic data can be stratified across quality and utilization data (e.g., claims) to provide a better understanding of where disparities occur and who they impact. The federal government, states, and managed care organizations (MCOs), however, continue to face challenges in collecting complete, accurate, and consistent demographic data.

When demographic data cannot be collected directly from individuals, other data sources can be used. One example is the data collected from the U.S. Census Bureau. During the COVID-19 pandemic, the U.S. Census Bureau deployed a new survey, the Household Pulse Survey, to quickly and efficiently deploy data collected on how the COVID-19 pandemic was impacting the lives of Americans.[1] The survey collected SOGI data and identified that LGBTQ+ (lesbian, gay, bisexual, transgender, queer, and others) individuals were disproportionately impacted by economic disparities compared to non-LGBTQ+ individuals. Approximately 28% of LGBTQ+ individuals reported some form of job loss during the pandemic, compared to 18% of non-LGBTQ+ respondents.

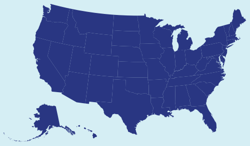
When paired with REL data, LGBTQ+ individuals of color experienced even greater disparities. Approximately 60% of Black LGBTQ+ individuals and 71% of Hispanic or Latino LGBTQ+ individuals reported some form of job loss.[2]

Data Challenges

Data are core to health equity efforts. They not only help to identify if health disparities exist, but also can help target and evaluate interventions to address those disparities. Unfortunately, incomplete, inaccurate, and inconsistent demographic data are one of the biggest barriers to understanding the full extent of health disparities that exist across communities. To address this challenge, Medicaid and the health care system broadly must improve the collection and reporting of demographic data.

The Medicaid and CHIP Payment Access Commission (MACPAC) recently released a brief outlining the availability of race and ethnicity data for Medicaid beneficiaries by state.[3] The report examined the Transformed Medicaid Statistical Information System (T-MSIS) and found that most states had missing race and ethnicity data for a significant portion of Medicaid beneficiaries. Regarding race data, 23 states reported missing race data for approximately 10-30% of their Medicaid enrollees, including three states that are missing race data for over 50% of their Medicaid population. While not as troublesome as race data completeness, ethnicity data also has gaps. In total, nine states reported missing or unknown ethnicity data for their Medicaid population.

23 states
reported missing
race data



9 states
reported missing or unknown
ethnicity data

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[1] Household Pulse Survey Data Tables (census.gov)

[2] New U.S. Census Bureau data show significant economic disparities among the LGBTQ+ community – Equitable Growth

[3] Availability of Race and Ethnicity Data for Medicaid Beneficiaries (macpac.gov)

While the need to improve the collection and reporting of demographic data is known, there are many challenges that currently exist that complicate efforts to do so. The following must be addressed to improve data collection and reporting:

- **Non-Standardization:** The Department of Health and Human Services (HHS) provides guidance developed by the Office of Management and Budget (OMB) around collecting REL data. There is, however, no mandate or requirement that states use any of the standards provided. State Medicaid programs therefore do not have required standards for their current data collection efforts for REL or SOGI data. Lack of data standardization creates significant variations in the data collected – data may be collected differently for different purposes and may also be stored in different systems or databases, further complicating the issue of aggregation and application.
- **Fragmented Data Collection:** States use a variety of data sources across siloed data systems to capture demographic data. Furthermore, challenges related to data sharing between state data systems and stakeholders prevent the capturing and reporting of all relevant data necessary to address inequities at the individual and population level. These challenges include duplicating efforts, tapping limited resources, and burdening the individual whose data is collected. Data collection and reporting efforts are further fragmented as different systems often collect data inconsistently, making it difficult to compare data collected.
- **Poor Data Quality:** States and MCOs have access to aggregated beneficiary data, but the data available are not always accurate and necessary demographic data can be missing or incorrectly collected. Quality measures and interventions targeted at addressing specific health disparities require accurate, high quality disaggregated data.[4] In addition, how demographic data is collected (e.g., self-reported vs. imputed) creates further quality concerns.
- **Avoiding Harm:** The general history of collecting demographic data such as race, ethnicity, language, and gender creates concern about the application of these data for discriminatory practices. This has led to complex consumer protection laws. In a survey from the American Medical Association, over 90% of survey participants voiced concern over who has access to their data.[5] Efforts to increase or even standardize data collection will need to consider these concerns and the need for legal protections while balancing the value of collecting these data (i.e., one cannot be compelled to provide race information, data cannot be used with criminal intent), and include guardrails. Individuals should be given access to information about how the data will be used and protected.
- **Data Ownership: An important component of advocacy in this space would be a comprehensive ethical framework regarding the collection of demographic data.** Specifically, systems must allow patients to control their own data, including who it is shared with and when.
- **Incomplete Collection:** In many states, data around disability status, sexual orientation, and/or gender identity are rarely collected. This lack of collection can hide existing health disparities from being uncovered.
- **Collector Discomfort:** Individuals may feel a sense of discomfort when providing demographic data. This may lead to the omission of answers and therefore incomplete data. In addition, discomfort could lead to data collectors inputting data without asking. For example, instead of asking an individual what their race or ethnicity is, the data collector may assume the answer based off appearances and not obtain the data directly from the consumer. When collecting demographic data, it is essential to preserve respect and privacy.

834-Enrollment File Challenges

The 834-enrollment file is the method that insurance coverage sponsors – employers, state Medicaid agencies, and Medicare – use to transmit enrollment information to payers. (Note, for the purposes of this report, we will focus on 834-enrollment files sent from state Medicaid agencies to Medicaid payers.) While helpful in many ways, 834-enrollment files often inhibit equity efforts in several ways, including:

Example: COVID-19

A recent example of data gaps impacting health outcomes was highlighted due to the COVID-19 pandemic. In the early days of the pandemic, many states were not reporting race and ethnicity data for COVID-19 cases, hospitalizations, and deaths. While we know the COVID-19 pandemic has disproportionately impacted people of color, comprehensive data to fully understand disparities was limited and delayed.

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[4] Advancing Health Equity Requires More and Better Data | KFF

[5] AMA Survey: Most Patients Concerned About Health Data Privacy | InsideHealthPolicy.com

- **Non-Standardization:** States do not have standardized 834-enrollment data templates. This has resulted in a significant variation in the types of demographic data states include or do not include in their 834-enrollment files. For example, states may not include race in the 834-enrollment files they send to Medicaid payers.
- **Terminology:** In many states, 834-enrollment files have data that can be prescriptive or use archaic terminology, leading to inaccurate data capturing. This includes not allowing individuals to select more than one option for race (and/or not including multiracial options), or only viewing gender binarily– only listing male and female as options. These limited options may result in individuals not disclosing information as they feel the choices available do not represent their individual, unique selves.
- **Fear and Stigma:** Medicaid beneficiaries may not want to share their information due to concerns around how their information will be used or the stigma associated with pursuing public benefits.

Improving the collection and reporting of demographic data is critical to gaining an understanding of both individual and population characteristics, including what disparities exist, and subsequently working to improve the health outcomes of communities.[6]

Efforts to Advance Data Availability

State Efforts

In its annual June report to Congress, MACPAC included a chapter dedicated to health equity for the first time.[7] In the chapter, the Commission identified specific policy levers in Medicaid that can be used to support health equity. One lever was data collection and reporting, but only if specific challenges related to self-reporting and inconsistent data collection methods are addressed.

There is currently wide variation in how and what data states are capturing that could support their health equity efforts. Specific to REL data, an analysis conducted by the State Health Access Data Assistance Center (SHADAC)[22] revealed that there is variability in the number and type of race and ethnicity categories that states use. In another analysis of REL data in 14 states conducted by CMS[23] more than 20% of the data was missing. States are utilizing a number of strategies specific to improving their REL data completeness:

- Requiring MCOs and other contractors to collect REL data and/or accepting data collected by those entities to support agency collected data
- Updating communication materials to explain how REL data will be used and/or why reporting data are important
- Linking with other agencies or sources of data to obtain additional REL data
- Incentivizing entities such as hospitals and health systems to provide complete REL data
- Soliciting stakeholder feedback on how they can better address the need to collect this data and streamline the collection process

States are also continuing to use Medicaid managed care procurements to emphasize the need for REL and other related data. State Medicaid agencies should continue to look to their MCO partners to help improve the completeness and accuracy of Medicaid consumer data and to supplement state capabilities surrounding data collection and reporting.

Federal Efforts

In early 2022, the Centers for Medicare and Medicaid Services (CMS) Office of Minority Health (OMH) released their Framework for Health Equity.[10] To help inform future health equity efforts, the framework identified five priorities for reducing health disparities and advancing health equity. One of the priorities is focused directly on data –

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[6] SHVS-50-State-Review-EDITED.pdf

[7] June 2022 MACPAC Report to Congress

[22] How the Pandemic Continues to Shape Medicaid Priorities: Results from an Annual Medicaid Budget Survey for State Fiscal Years 2022 and 2023 – Health Equity – 10030 | KFF

[23] Race/Ethnicity Data in CMS Medicaid (T-MSIS) Analytic Files Updated December 2021 – Features 2019 Data | SHADAC

[10] Centers for Medicare and Medicaid Services

"Expand the Collection, Reporting, and Analysis of Standardized Data." Within this priority, CMS "strives to improve [their] collection and use of comprehensive, interoperable, standardized individual-level demographic and social determinants of health (SDOH) data, including race, ethnicity, language, gender identity, sex, sexual orientation, disability status, and SDOH." By improving the collection, analysis, and reporting of data, CMS can work toward the goal of reducing disparities and advancing health equity.

There are several efforts CMS has underway that reaffirm their commitment to improving the collection and reporting of demographic data. Examples of current efforts include:

- The Center for Medicare & Medicaid Innovation (CMMI) will require all new model participants to collect and report demographic data of their enrollees and, as appropriate, data on social needs and SDOH.[11]
- CMS is working with states to improve measurement of health disparities across a core set of stratified metrics.[12]
- CMS continues its collaboration with the HHS Office of the National Coordinator for Health Information Technology (ONC) and others to advance interoperability and bring administrative and clinical data together.[13]

In addition, the federal COVID-19 Health Equity Task Force developed formal recommendations to address data issues inhibiting advancement of health equity efforts at the federal level.[14] The Task Force recommended:

- Compiling a registry for primary care practices to identify and track patients with detailed demographic, social, and medical history;
- Mandating requirements for granular race and ethnicity data fields; and
- Establishing nationally standardized categories of race and ethnicity data fields and other identifying information.

Opportunities

There are opportunities for the federal government, state Medicaid agencies, and MCOs to improve demographic data collection to help address disparities and advance health equity.

Opportunities include:

- **Standardizing data elements.** By creating standard demographic data elements that stakeholders must use, consistent and comparable data can be collected and reported across the Medicaid system.
- **Developing guidance for state Medicaid agencies.** CMS could consider developing guidance outlining best practices for data collection and reporting, as well as recommended data templates. Guidance should include recommendations on 834-enrollment form changes and use.
- **Incentivizing data collection.** State Medicaid agencies can offer incentives to Medicaid MCOs to collect and report beneficiary demographic data. If a MCO can obtain data from beneficiaries, this data can be shared back with state Medicaid agencies.
- **Researching data collection.** Targeted research on the current state of demographic data collection and reporting within Medicaid, and likely the health care system as a whole, could help to identify promising practices and training materials.
- **Transparency with stakeholders and Medicaid consumers.** One factor that could impact the disclosing of demographic data is not fully understanding why the data is needed or what it will be used for. Medicaid beneficiaries and supporting stakeholders could be educated on the importance of collecting demographic data and efforts should be made to clearly articulate how data is used, with specific focus being placed on the role data plays in reducing disparities.

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[11] Strategic Direction | CMS Innovation Center

[12] Paving the Way to Equity: A Progress Report 2015-2021 (cms.gov)

[13] Former National Health IT Coordinators Respond To Proposed ONC, CMS Interoperability Rules | Health Affairs

[14] COVID-19 Health Equity Task Force

Part 3: Health Equity & The Role of the Delivery System

Since Medicaid's creation in 1965, the program has worked to provide unbiased access to care that is culturally competent and responsive to enrollees' individual needs. As discussed in Part 1, Medicaid agencies are intentionally working to improve health equity as awareness of health disparities and inequities has grown. States are partnering with managed care organizations and advancing program design features to strengthen, mobilize, and redefine the healthcare delivery system.

Partnering with Managed Care

States oversee structural requirements, processes and activities, and reporting requirements that establish the basis for how MCOs deliver services to enrollees.[24,25] A growing number of states are leveraging their programmatic design to deliberately focus operations and performance toward advancing health equity.

To support their state partners in improving health equity within the Medicaid, several MCOs, including UnitedHealthcare, have taken the following actions: **Standardizing data elements.** By creating standard demographic data elements that stakeholders must use, consistent and comparable data can be collected and reported across the Medicaid system.

- **Resourcing care teams with more Community Health Workers, expertise in areas of health-related social needs like housing and employment, establishing health equity directors to ensure consistent, thoughtful focus on advancing health equity.**
- **Training and engaging staff across the health plan** on topics related to diversity, equity, and inclusion, including cultural competency and humility, racial equity, and implicit bias.
- **Developing Health Equity Action Plans that document** members' needs, work to meet those needs in a culturally competent manner, and design and implement programs, interventions, and services that address disparities and social needs.
- **Leverage advisory committees inclusive of members, providers and community members to identify, develop and evaluate interventions to address health outcomes for community members.**

Leveraging Quality Reporting & Accreditation

As noted in the section on data, accurate and complete demographic data (e.g., race, ethnicity, language, sexual orientation, gender identify, disability status, and geography) is essential to ensure meaningful stratification of quality measures necessary to help identify and address health disparities.

In 2022, the National Committee for Quality Assurance (NCQA) announced race and ethnicity stratifications to five HEDIS measures. As the industry quality leader, NCQA also added race and ethnicity data, social determinants of health screening measures, and gender-relevant care measures to its 2023 health plan quality rankings.[26]

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[24] Medicaid and CHIP Payment and Access Commission

[25] Medicaid and CHIP Payment and Access Commission

[26] National Committee for Quality Assurance

State can leverage national sets of standards in designing and implementing programs that advance health equity. The two most commonly leveraged include:

- **National Standards for Culturally and Linguistically Appropriate Services (CLAS) in Health and Health Care:** Developed by the Office of Minority Health in the U.S. Department of Health & Human Services, these serve as a blueprint for implementing culturally and linguistically appropriate services. There are 15 standards related to topics such as governance, communication and language assistance, and engagement and accountability.[27] Multiple states require MCOs to meet a portion, if not all, of the standards, particularly in terms of member engagement.[28]
- **NCQA Health Equity Accreditation Programs:** NCQA provides several accreditations for health plans related to quality including two for health equity. The **Health Equity Accreditation** is intended to help organizations build a strong foundation for evaluating and surfacing members' needs, including standards for identifying opportunities to reduce health inequities and improve care and collecting data to understand the linguistic and cultural needs of their members. Building upon that groundwork, **Health Equity Accreditation Plus** focuses on collecting social risk data, acting on the data, developing community partnerships, and building meaningful opportunities for patient and consumer engagement.[29]

Recruitment, Retention, and Promotion of Clinicians from Underrepresented Communities

The recruitment, retention, and promotion of a diverse workforce that resembles the makeup of the populations served is a key strategy for advancing health equity. Research shows diverse perspectives to an organization's decision-making process ensures that the organization is more responsive to members' needs. Racial, ethnic, and gender concordance between patients and physicians is associated with:[30]

- improved patient satisfaction,
- decreased bias in clinical care,
- longer visits, and
- improved patient outcomes.

While states work to strengthen and expand the clinical workforce to meet care demands, there is interest in solutions that engage populations that have been historically underrepresented in the health care workforce including Black, Hispanic, and American Indian/ Alaska Native populations.[31]

Addition of New Providers

Medicaid programs are also interested in maximizing the capacity of existing providers to better meet the needs of their members. Many now look to allied health professionals who can supplement clinical capacity and work at the intersection of health and community. Two professions gaining recognition in the Medicaid program are CHWs and doulas, both of whom play key roles in providing Medicaid members with culturally competent care.

- **Doulas:** According to the March of Dimes, Black and American Indian/Alaska Native women are 60% more likely to give birth to a preterm baby compared to White women.[32] Doulas are non-clinical professionals who provide physical, social, and informational support to pregnant individuals throughout the various stages of pregnancy — from prenatal care to labor and delivery and post-partum care. Having a care team that includes a doula has been shown to positively improve maternal outcomes for Black, Indigenous, and people of color (BIPOC). Currently, there are five states currently covering doula services as a benefit in Medicaid including Maryland, Minnesota, New Jersey, Oregon, and Virginia.[33]
- **Community Health Workers:** CHWs have strong ties to underserved communities and provide a wide range of services addressing the health and social needs of these communities. States can provide reimbursement for CHW services through Medicaid under state plans or Section 1115 demonstration authorities. In states that do not reimburse for CHW services,

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[27] Culturally and Linguistically Appropriate Services – Think Cultural Health (hhs.gov)
[28] State Health & Value Strategies
[29] National Committee for Quality Assurance
[30] Institute of Medicine
[31] Association of American Medical Colleges
[32] March of Dimes
[33] National Academy for State Health Policy

many MCOs still directly employ CHWs through administrative spend because of the value they add to the communities they serve. There remain significant opportunities to expand the use and reimbursement of CHWs in Medicaid, as only 21 states currently reimburse for CHW services.[34] There is growing interest of CHW services in Medicare as well as Medicaid. The proposed 2023 Physician Fee Schedule for Medicare includes CHW reimbursement.[35]

Benefit Design

To deliver access to care that is culturally competent and responsive to enrollees' individual needs, states are adding new services and enabling increased flexibility for MCOs and providers to meet members where they are in the community. This has included such actions as:

- expanding the availability of services in schools to meet the needs of children and youth;
- providing a medical respite care benefit to offer individuals experiencing homelessness a safe place to rest, recuperate, and receive follow-up services after a hospital visit;
- allowing certain services to be delivered via audio-only telehealth to overcome digital barriers to care; and adding traditional healing services as a covered benefit; and
- reimbursing providers for completing social risk assessments and connecting patients to the needed services and supports.

In their efforts to address health disparities, states are increasingly looking to leverage in-lieu of services (ILOS), which are a substitute for covered services and may qualify as a covered service for the purposes of capitation rate setting. To use ILOS, states must determine that ILOS are medically appropriate and cost effective. ILOS can facilitate innovative and focused services and solutions, based on individual members' unique needs.

Members are not required to use the alternative service or setting but may choose to do so. Approved ILOS are authorized and identified in MCO contracts and costs associated with ILOS may be included in the numerator of the medical loss ratio (MLR) and are considered when developing managed care capitation rates. ILOS can substitute for and potentially decrease utilization of a range of covered benefits, such as hospital care, nursing facility care, and emergency department use. ILOS can help states and MCOs address social risk factors as they provide increased flexibility to offer medically appropriate services in community settings. ILOS can help to address the most complex challenges affecting health such as homelessness, unstable and unsafe housing, food insecurity, and/or other social needs. Examples of such ILOS include housing tenancy and sustaining services, housing deposits, and medically tailored meals.

Alternative Payment Models

As noted previously, the federal government established health equity as the first pillar of its 2022-2026 strategic plan and is promoting alternative payment models (APMs) in Medicare and Medicaid as a means to advance health equity. Efforts from the administration include:

- new expectations for providers in annual Medicare fee schedules;[36,37]
- design modifications to existing programs like the Medicare Shared Savings Program;[38]
- development of the new ACO Realizing Equity, Access, and Community Health (REACH) model focused on Medicare providers in underserved communities that incorporates such features as the development and implementation of a health equity plan, quality goals focused on health disparities, and the collection demographic and social need data;[39]
- a new strategy for the Center for Medicare and Medicaid Innovation (CMMI) that commits to considering health equity at every stage of model design, implementation, and evaluation and places a greater emphasis on Medicaid and rural and safety-net providers to achieve equitable outcomes;[40]

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[34] National Academy for State Health Policy
[35] Centers for Medicare & Medicaid Services
[36] Centers for Medicare & Medicaid Services
[37] Centers for Medicare & Medicaid Services
[38] Centers for Medicare & Medicaid Services
[39] Centers for Medicare & Medicaid Services
[40] Centers for Medicare & Medicaid Services

- release of industry guidance for equity-centered design in APMs via the Health Care Payment Learning and Action Network (LAN);[41] and
- launch of a new State Transformation Collaboratives program that brings CMS to the table with the Medicaid agency, providers, members, and other stakeholders in select states to develop new APMs.[42]

In addition to federal activity, many states are encouraging Medicaid MCOs and providers to participate in APMs that address health disparities and social barriers to health.

Community Engagement

As discussed in Part 1, inequities and health disparities are rooted in historical and current realities of differential access to opportunity and decision-making authority. Addressing inequities and disparities requires strategies informed by the deep knowledge and lived experience of community members and stakeholders and the collaborative efforts of policymakers, heath plans, providers, community- and faith-based organizations, and members. States and MCOs are prioritizing community engagement and partnership by:

- Engaging members and providers to identify root causes of inequities and inform strategies to reduce inequities.[43]
- Participating in community-led initiatives like collaborating in community health needs assessments and partner with CBOs to address socioeconomic and/or environmental issues.
- Reinvesting in communities they serve to build capacity.[44]

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[41] Health Care Payment Learning & Action Network
[42] Health Care Payment Learning & Action Network
[43] State Health & Value Strategies
[44] Manatt, Phelps & Phillips, LLP

Part 4: Health Equity & Populations Served by the Medicaid Program

According to the latest data from the Centers for Medicare and Medicaid Services (CMS), over 81 million individuals are enrolled in Medicaid.[45] Due to its structure, the Medicaid program largely provides health care coverage to underserved populations – children, pregnant individuals, medically needy individuals, low-income adults, elderly adults, and individuals with disabilities. Over 6.9 million Medicaid beneficiaries are age 65 or older and nearly 7 million individuals with disabilities under 65 have health care coverage through Medicaid.[46] Medicaid beneficiaries with disabilities include individuals with physical disabilities, intellectual and developmental disabilities (I/DD), behavioral health diagnoses, traumatic brain injuries, and other disabilities and chronic conditions. Medicaid also serves the dually eligible population by helping to cover Medicare premiums and/or cost-sharing and providing coverage for a range of services that private insurance and Medicare do not cover (e.g., long-term services and supports [LTSS] in nursing homes and the community).[47]

> **"The sheer volume of the program [Medicaid] suggests that there is no meaningful pathway to national equity that does not involve the Medicaid program," said Chima Ndumele from Yale University, who moderated the panel.**

SOURCE: Improving Health Equity in Medicaid: What Are the Challenges and Opportunities? | AcademyHealth

Medicaid also serves disproportionately high numbers of racially and ethnically diverse populations. More than half of all adults and more than two-thirds of children enrolled in Medicaid and the Children's Health Insurance Program (CHIP) identify as Black, Hispanic, Asian American and Pacific Islander, American Indian/Alaska Native, or multiracial.[48] Given these demographic characteristics, a high proportion of the populations covered by Medicaid are likely to be impacted by health disparities. This has incentivized both the federal government and state Medicaid programs to place an emphasis on reducing health disparities and promoting health equity. As described in Part 1, at the federal level, the Department of Health and Human Services (HHS) and CMS have made commitments to prioritize health equity. State Medicaid programs have also shared their intentions and initial steps to promote health equity, and many are examining their programs and policies to support that goal. Below are additional details about the health disparities faced by Medicaid covered populations and the health equity-focused policy and procurement trends associated with each.

Health Equity by Medicaid Population – Core Medicaid

Children and Adolescents

Together, Medicaid and CHIP provide coverage for almost half of our country's children and young people. Between February 2020 and January 2022, child enrollment in Medicaid and CHIP grew by 14.4% to over 40 million.[49] In addition, recent data released by CMS show that 1.3 million children were enrolled in marketplace plans during the 2022 Marketplace Open Enrollment period.[50]

Based on these current coverage numbers, children ages 0-18 currently make up roughly half of the entire Medicaid population. A disproportionate share of the child Medicaid population identifies as Hispanic (37.5%) compared with their representation in

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[45] April 2022 Medicaid and CHIP Enrollment Snapshot
[46] Medicaid Financial Eligibility for Seniors and People with Disabilities: Findings from a 50-State Survey – Issue Brief – 9318 | KFF
[47] Medicaid's Role for Medicare Beneficiaries – Issue Brief – 8980 | KFF
[48] Chapter 6: Medicaid's Role in Advancing Health Equity (macpac.gov)
[49] The Latest on Child Medicaid and CHIP Enrollment During the Pandemic – Center For Children and Families (georgetown.edu)
[50] Exchange 2022 Open Enrollment Report

the total child population (25.6%). There is similar disproportionate representation among the Black, non-Hispanic population (20.8% versus 12.7% respectively).[51]

Despite the recent increases in enrollment in Medicaid, CHIP, and the Marketplaces, over 3 million children are still uninsured, and disparities exist among this population. American Indian/Alaska Native children have the highest uninsured rates (11.8%), followed by those who are Hispanic (11.4%) and non-Hispanic, Black (5.9%).[52]

Beyond coverage, disparities exist in the prevalence of health care needs and care access for certain demographics of children and adolescents. Black, non-Hispanic, American Indian/Alaska Native, and multi-racial children are more likely to report having a chronic condition (e.g., asthma) than white, non-Hispanic children.[53] Similar disparities exist with regard to care access such as well-child checkups with white, non-Hispanic children more regularly accessing health care services. Additionally, non-white children and adolescents are more likely to experience delays in care due to access barriers such as cost, inflexible schedules, and lack of transportation.[54] Specific to behavioral health care, an estimated 16.5% of children and youth ages 6-17 have at least one mental health disorder, yet nearly 50% do not receive needed treatment or services.[55] This rate is higher for children and youth of color. Those who live in rural areas also face disproportionate barriers to accessing these services.[56]

The COVID-19 pandemic has played a particularly impactful role on the health and well-being of children. The trauma of COVID-19 itself and the education, economic, and social justice challenges of the time have also played an outsized role in young people's lives, particularly for children and youth of color. Both federal and state policymakers have prioritized addressing the coverage gap disparities that exist for children and adolescents along with supporting access issues that lead to inequitable outcomes for the population.

Federal and State Actions

Federal

In an effort to help bridge racial and demographic disparities in health care coverage for children and adolescents, the CMS recently awarded $49 million in grants to 36 entities through the Connecting Kids to Coverage program.[57] Much of the funding was targeted for low-income communities with low coverage rates and allocated to local, community-based organizations and schools that are known and trusted voices. In addition, both Congress, through the Bipartisan Safer Communities Act, and the administration through regulation and grant making, have prioritized schools as key partners in supporting not only health care coverage for children but also access to needed services.[58] Schools serve as critical partners in helping to enroll children in programs they are eligible for, such as Medicaid, along with ensuring that needed services are made available without charge to children thereby helping to increase health equity.

Along with efforts to address disparities in health care coverage, the administration has also prioritized initiatives to address the developing crisis in children's behavioral health care. These actions have included issuing a joint letter encouraging states, tribes, and local jurisdictions to maximize their efforts to implement meaningful and equitable approaches to both identify and address the behavioral health needs of children and adolescents.[59]

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[51] Chapter 6: Medicaid's Role in Advancing Health Equity (macpac.gov)

[52] CMS Awards Funding to Boost Medicaid Enrollment

[53] Access in Brief: Experiences in Accessing (macpac.gov)

[54] Ibid.

[55] Prevalence of Mental Health Disorders and Disparities of Mental Health Care Use in Children

[56] Racial and Ethnic Disparities in Pediatric Mental Health – PMC (nih.gov)

[57] Connecting Kids to Coverage

[58] Guidance on School-Based Health Services

[59] Joint Letter on Children's Mental Health (hrsa.gov)

State

States are using both policy and procurement levers to help address disparities in health care coverage and health outcomes among children and adolescents. One emerging policy trend focused on supporting coverage is multiyear continuous eligibility. Currently, twenty-four states offer 12-month continuous eligibility to all children enrolled in CHIP and Medicaid through State Plan Amendments (SPA)[60], but there is no SPA option for states to provide continuous eligibility for children beyond one year.

Over 70% of individuals accessing health care coverage through Medicaid are served by a managed care organization (MCO). That number jumps to 80% for children enrolled in Medicaid.[61] As a result, in addition to policy actions, a number of states are utilizing the procurement process to prioritize a focus on improving health equity for their child and adolescent populations.

Expansion Population

Through the Affordable Care Act (ACA), states have the authority to extend Medicaid coverage to nearly all adults with incomes up to 138% of the FPL. To date, over 20 million Americans have gained health care coverage through the Medicaid expansion pathway. Extending health coverage to more low-income people is an important way to reduce health disparities.[62]

An analysis by the Kaiser Family Foundation found that Medicaid expansion particularly affects people of color, given that they are more likely to lack health insurance.[63] In states that have not adopted Medicaid expansion, adults with incomes below the FPL fall into a coverage gap because they remain ineligible for Medicaid but earn too little to qualify for premium tax credits for qualified health plans in the Marketplace. As a result, they are likely to remain uninsured. More than half of uninsured adults who would be eligible for Medicaid if all states expanded are people of color.[64]

In addition to the impact on access to coverage through Medicaid expansion for people of color, individuals in rural communities have also benefited. One study found increased coverage and decreased uninsurance rates among rural community health center patients in Expansion states.[65]

Federal and State Actions

Federal

As of August 2022, 39 states (including the District of Columbia) have adopted Medicaid expansion.[66] If the remaining states expanded Medicaid, nearly 4 million uninsured low-income adults could gain coverage. Among those gaining coverage would be over 2 million people now in what is referred to as the coverage gap — that is, people whose incomes are below the poverty line, and thus ineligible for premium tax credits for marketplace coverage, but who are ineligible for Medicaid under their state's rules.

The administration has prioritized both health equity and protecting and expanding access to health care coverage.[67] In support of these priorities, the administration worked with Congress to include a provision in the American Rescue Plan that would increase a state's base Federal Medical Assistance Percentage (FMAP) by 5% for five years on their non-Expansion population if they adopted Medicaid expansion. However, the provision is still optional and to date no state that has yet to expand Medicaid has done so and accessed this additional federal funding.

State

A total of six states have now adopted Medicaid expansion by ballot initiatives that had previously chosen to expand.[68]

Pregnant Individuals & Infants

Pregnant individuals in the United States experience adverse maternal and birth outcomes at rates greater than those in nearly all other developed nations. The U.S. maternal mortality rate in 2019 was 20.1 deaths per 100,000 live births, an increase from 17.4 in the previous year with more than half of recorded maternal deaths occurring the day after birth.[69]

Significant health disparities exist in these maternal health outcomes driven by race, ethnicity, geographic location, and socio-economic status.

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[60] State Adoption of 12-Month Continuous Eligibility for Children's Medicaid and CHIP | KFF
[61] Medicaid Managed Care Research: 2022 in Review
[62] Centers for Medicare and Medicaid Services (CMS) Medicaid and CHIP Enrollment Data
[63] Effects of the ACA Medicaid Expansion on Racial Disparities in Health and Health Care
[64] Who Could Be Reached by Medicaid Expansion?
[65] Medicaid Expansion and Community Health Centers
[66] Status of State Medicaid Expansion Decisions
[67] The Biden-Harris Administration Immediate Priorities
[68] Medicaid Expansion Ballot Measures
[69] Medicaid Expansion Ballot Measures

Black women are 3 to 4 times more likely to die from childbirth than white women.[70] For every maternal death, more than 100 women experience severe maternal morbidity (SMM).[71] Women with SMM are more likely to be low-income, older, delivered by cesarean, Black, and enrolled in Medicaid. Black women have a preterm birth rate 49% higher than all other women.[72] The percentage of infants born with low birthweight is two times higher among Black than white mothers.[73] Low birthweight infants — babies weighing less than 2,500 grams at birth — are at increased risk of infant mortality and a host of short- and long-term complications. Black infants have 2.3 times the infant mortality rate as non-Hispanic white women.[74]

Geographic and socio-economic factors also significantly impact the maternal mortality rate. According to publicly available data from the U.S. Centers for Disease Control and Prevention (CDC), rural areas had a pregnancy-related mortality ratio of 29.4 per 100,000 live births versus 18.2 in urban areas in 2015.[75] According to the March of Dimes, more than 2.2 million women live in "maternity care deserts" with a lack of maternity care providers, no birth centers, and no hospital offering obstetric care. Rural women are 9% more likely than urban women to experience a composite measure of severe maternal morbidity and maternal mortality. Infant, neonatal, and post-neonatal mortality rates are higher in rural than urban counties.[76]

Nationally, Medicaid covers 45% of all births and about two-thirds of births to Black, non-Hispanic women and thus has a significant opportunity to impact these inequities.[77] In one analysis of 14 states, an estimated $114-$214 million of savings to Medicaid would be realized if racial and ethnic disparities in maternal outcomes, such as rates of preterm birth, preeclampsia, and gestational diabetes, were reduced.[78]

Federal and State Actions

Federal

The maternal health crisis has been prioritized by federal policymakers in both the administration and Congress. As part of its broader focus on health equity and its intersection with maternal health, the Biden administration held the first ever federal Maternal Health Day of Action in December 2021. The Day of Action included highlights of current federal activities, the announcement of new policies, and the detailing of public and private partnerships underway to tackle the maternal health crisis.[79] More recently, the White House issued their Blueprint for Addressing the Maternal Health Crisis[80] followed by the release of a Maternity Action Plan[81] by CMS.

In addition, a contingent of the Congressional Black Maternal Health Caucus has been championing legislation focused on the maternal health crisis, including a comprehensive package of bills known as the Momnibus.[82] Maternal health related provisions have also been considered as part of COVID-19 relief legislation and the Build Back Better legislative debates.

The focus of these federal efforts has largely fallen into five areas:

1. Access to and coverage of comprehensive, high quality maternal health services
2. Availability of accountable systems of care
3. Advancement of data collection and utilization
4. Expansion and diversification of the perinatal workforce
5. Strengthened economic and social supports

Examples of specific policy and regulatory actions taken by the federal government in support of addressing inequitable maternal health outcomes include:

- **Postpartum Coverage Expansion:** The American Rescue Plan Act provided a state plan option for states to expand postpartum coverage in Medicaid for 12 months for up to five years.

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[70] Ibid.
[71] A global view of severe maternal morbidity: moving beyond maternal mortality
[72] Preterm Birth | Maternal and Infant Health | Reproductive Health | CDC
[73] Differing Birth Weight among Infants of U.S.-Born Blacks, African-Born Blacks, and U.S.-Born Whites | NEJM
[74] Preterm Birth | Maternal and Infant Health | Reproductive Health | CDC
[75] Pregnancy Mortality Surveillance System | Maternal and Infant Health | CDC
[76] National Partnership for Women's and Children's Health
[77] Medicaid Initiatives to Improve Maternal and Infant Health and Address Racial Disparities
[78] Racial Disparities in Economic and Clinical Outcomes of Pregnancy Among Medicaid Recipients
[79] Maternal Health Day of Action December 2021
[80] White House Blueprint for Addressing the Maternal Health Crisis
[81] Cross-Cutting Initiative: CMS Maternity Care Action Plan
[82] Black Maternal Health Momnibus Act of 2021

- **"Birthing Friendly" Hospital Designation:** In fall 2023, CMS will begin awarding a new quality designation to hospitals that meet the criteria of the recently established Maternal Morbidity Structural measure.[83] The measure's criteria include an attestation that will capture whether a hospital participated in a national or statewide quality collaborative and implemented all recommended interventions. CMS intends to propose a more robust designation, which may include the two health perinatal measures in the Hospital Inpatient Quality Reporting Program.
- **Perinatal Workforce and Support Guidance:** CMS released a State Health Official Letter (SHO 21-117) that included language encouraging states to consider coverage of doula services, home visiting, and other person-centered supports and services.[84]
- **Medicaid Postpartum Care Equity Assessment:** CMS is conducting an equity assessment on the quality of postpartum care in Medicaid and CHIP. CMS is looking at Medicaid and CHIP data to identify disparities and opportunities to address inequities in postpartum care.

State

As with the federal government, states are prioritizing actions focused on addressing the adverse and inequitable health outcomes faced by their pregnant and postpartum Medicaid enrollees. States are using both their available policy and programmatic levers to advance this focus on health equity in the maternal health space.

Specific examples include:

- **Extending Postpartum Coverage:** Utilizing the authority granted by the American Rescue Plan Act (described above), to date, 26 states and Washington, D.C. have received approval from CMS to extend coverage to 12 months for this population. There are additional states that have submitted SPAs and are awaiting CMS approval.
- **Adding Doula Care:** As a non-clinical provider, doulas support pregnant individuals most at risk of poor outcomes and have been shown to make pregnancy safer and improve outcomes for BIPOC pregnant and postpartum individuals. Currently, six states are covering doula care as a Medicaid benefit with a number more pursuing the option.
- **Refining Quality & Performance:** Required reporting on measures related to health equity with particular focus in many states on maternal health specific quality metrics.

In general, there is a lack of consistent and reliable data for these historically underserved populations. As a result, it is difficult to articulate the extent of health disparities across all races, ethnicities, sexual orientations, genders, and disabilities for the complex care populations. Additionally, it hinders the development of targeted interventions to address current documented health disparities.

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[83] Maternal Morbidity Structural Measure
[84] State Health Official Letter # 21-007

System Involved: Child Welfare and Justice-Involved

Over 500,000 children and youth interact with the child welfare and juvenile justice systems every year.[85] Across this population, there is disproportionate representation of children and adolescents of color. Black youth make up 14% of the population in the U.S. but 23% of the population of kids in foster care.[86] Youth who are LGBTQ+ face disparities within the child welfare system as well. Youth of color are also over-represented in the juvenile justice system. Nearly 67% of youth who are placed within the juvenile justice system are BIPOC but make up only 42% of the total youth population.[87]

Though only 3% of children without disabilities enrolled in Medicaid are in foster care, they account for 15% of behavioral health services used by all children on Medicaid.[2] Children and youth in foster care are also four times more likely to be prescribed psychotropic medications than other Medicaid adolescent members, and represent 13% of all Medicaid members, of all ages, who receive psychotropic medications.[3] As many as 70% of children and youth in the juvenile justice system have a mental health diagnosis.[4]

~67% of youth who are placed within the juvenile justice system are **black, Indigenous, and people of color (BIPOC)**

In addition to the disparities that exist in the child welfare and juvenile justice systems, the imprisonment rate among Black adults is nearly six times the rate for white adults. Additionally, Black and Hispanic individuals represent disproportionately higher numbers of those justice-involved compared to their representation in the total adult population in the U.S. The justice-involved population is both disproportionately low-income and has higher rates of chronic health conditions and/or disabilities than the general population.

Federal and State Actions

The federal government has not taken specific actions through changes to Medicaid policy or regulations to address the health outcome inequities in the child welfare and juvenile justice populations. Largely, states have taken the lead, requiring specialized approaches to serving children and youth that typically require a trauma-informed approach to care.

Conversely, there has been significant federal and state action supporting coverage of and access to health care for the justice-involved population. Given the racial and ethnic disparities among the justice-involved population, the federal government and states' actions have direct health equity implications.

Federal

Based on current federal law, Medicaid cannot cover services provided to people while they are in jail or prison, with the exception of inpatient hospital stays lasting 24 hours or more. Known as the Medicaid Inmate Exclusion, this policy has existed since 1965 and prohibits federal Medicaid dollars from being used to pay for services for "inmates of public institutions," even if they are eligible for Medicaid. To clarify the distinction between coverage eligibility and payment for services, the CMS provided guidance to states that supports the temporary suspension of Medicaid coverage for inmates versus termination. In the guidance they note, "a temporary suspension process maintains the individual's eligibility for Medicaid and provides for continuity of care."[89] The SUPPORT Act, which became law in 2018, explicitly prohibits the termination of Medicaid eligibility for juveniles who are inmates of a public institution and instead requires suspension.[90]

In addition to efforts to distinguish between suspension versus termination of coverage, members of Congress introduced legislation that, if signed, would repeal the inmate exclusion policy as well as allow for payment of medical services 30 days prior to release from jail or prison.

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[85] The State of America's Children 2021

[86] KIDS COUNT Data Center

[87] Juveniles in Residential Placement, 2017

[88] Gap between number of blacks, whites in prison narrows

[2] https://www.chcs.org/media/Medicaid-BH-Care-Use-for-Children-in-Foster-Care_Fact-Sheet.pdf

[3] Ibid.

[4] https://ojjdp.ojp.gov/mpg/literature-review/mental-health-juvenile-justice-system.pdf

[89] smd21002.pdf (medicaid.gov)

[90] Ibid.

State

Where the federal government has not provided permanent authority, states are utilizing the Medicaid waiver and procurement processes available to them to support coverage and access to health care for the justice involved population.

- Thirteen states currently or previously required MCOs to provide care coordination services to enrollees prior to release from incarceration.[91]
- Eleven states are pursuing opportunities to support the provision of reentry services up to 30 days prior to release/discharge to the community.
- Twenty-three states have electronic, automated data exchange processes between corrections and Medicaid to facilitate suspension/reinstatement of Medicaid eligibility.
- At least one state has prohibited a person's Medicaid eligibility from being suspended or terminated for up 29 days after incarceration.

Additional states have incorporated that MCOs focus on justice-involved individuals as part of their overall population health strategies or as part of their broader prioritization to provide support to Medicaid populations to keep them in their homes and communities.

Massachusetts and Oregon recently had their waivers approved and are now authorized to provide health related social needs services, including tenancy supports, nutritional education, and food access, to their justice-involved populations living in the community and transitioning out of incarceration.

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[91] State Policies Connecting Justice-Involved Populations to Medicaid Coverage and Care | KFF

Health Equity by Medicaid Population – Complex Care Populations

In general, there is a lack of consistent and reliable data for these historically underserved populations. As a result, it is difficult to articulate the extent of health disparities across all races, ethnicities, sexual orientations, genders, and disabilities across the complex care populations. Additionally, it hinders the development of targeted interventions to address current documented health disparities.

Aged, Blind, and Disabled (ABD)

Individuals who are eligible for Medicaid through the Supplemental Security Income (SSI) pathway are also known as the aged, blind, and disabled (ABD) population. There are about 8 million individuals who are eligible for Medicaid through this pathway.[92] About one-third of Medicaid beneficiaries who qualify on the basis of disability do so through receipt of SSI.[93] SSI provides additional income for older adults and people with disabilities that have little to no income to help them meet their basic needs.[94] Individuals who are eligible for Medicaid through the SSI pathway receive coverage for mandatory Medicaid benefits such as inpatient and outpatient hospital services, laboratory and x-ray services, and transportation to medical care.[95] The level of services needed by individuals widely varies among the ABD population. Some individuals may need a high level of care and reside in a nursing home, while others may utilize home- and community-based services (HCBS) to support living in integrated community settings.

Although about 23% of Medicaid enrollees are ABD, they account for 64% of Medicaid spending on medical services.[96] The disproportionate spending further highlights the need to identify and address the needs and health disparities among the ABD population to ensure that everyone is receiving the high-quality care they deserve.

The Social Security Administration (SSA) publishes SSI program statistics that are segmented by various beneficiary characteristics like age and gender, but do not include race.[97] To overcome the absence of data for race categories, SSA researchers primarily use data from four major surveys—1) The Current Population Survey (CPS), 2) the Survey of Income and Program Participation (SIPP), 3) the American Community Survey (ACS), and 4) the Health and Retirement Study (HRS) – to examine the SSI program use by race and ethnicity.[98]

The report, "Why Researchers Now Rely on Surveys for Race Data on OASDI and SSI Programs: A Comparison of Four Major Surveys" examined the different advantages and limitations of using these surveys to analyze the demographics of SSI beneficiary and Old-Age, Survivors, and Disability Insurance (OASDI, or Social Security) populations. For example, two advantages of the CPS, SIPP, and HRS are the distinctions between SSI recipient types (old age and disability) and the possible data linkages with SSA's administrative data. Linking SSA's administrative data with survey data is to combine the data sources to create a new dataset with more demographic and socioeconomic information. In addition, the data linkages can help with data accuracy as the number of individuals reporting they receive SSI or OASDI payments in their survey responses can be checked against SSA's administrative data. While the ACS does not enable linkage with SSA administrative data, it is the only survey out of the four discussed that includes all institutionalized (e.g., individuals in prisons and nursing homes) and noninstitutionalized populations. Due to the inclusion of institutionalized populations, the ACS can collect more data on Black OASDI and SSI beneficiaries since they are overrepresented in correctional facilities and nursing homes. However, some limitations of the surveys include: the HRS excluding individuals younger than 51; the CPS and ACS not collecting data for SSI beneficiaries younger than 15; and the SIPP not providing local-level geographic data. With the various advantages and limitations of these surveys and it being optional for individuals to report their race and ethnicity, there are still gaps in the data.

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[92] SSI Recipients by State and County, 2020 (ssa.gov)

[93] People with disabilities: MACPAC

[94] Disability Benefits | SSA; Health coverage options for people who get Supplemental Security Income (SSI) Disability. | HealthCare.gov

[95] Mandatory & Optional Medicaid Benefits | Medicaid

[96] State Variation in Medicaid Per Enrollee Spending for Seniors and People with Disabilities (kff.org)

[97] Why Researchers Now Rely on Surveys for Race Data on OASDI and SSI Programs: A Comparison of Four Major Surveys (ssa.gov)

[98] Ibid.

It is difficult to understand and address racial disparities without a more widespread and consistent practice of collecting and reporting race and ethnicity data. In addition, without this data, it is impossible to assess whether previously documented racial disparities for SSI persist or have worsened. For example:

- A 1992 U.S. Government Accountability Office (GAO) report showed that Black applicants have consistently been allowed SSI benefits at lower rates than white applicants. In 1988, the allowance rate was 29% for Black SSI applicants, compared to 37% for white SSI applicants. GAO's analysis found that these racial disparities in allowance rates could not be explained by other key factors, such as age, impairment, or education.[99]
- A 2003 GAO report found that, among claimants without attorneys, Black claimants were significantly less likely to be awarded benefits compared to white claimants.[100] GAO also found that other factors – including sex, income, and the presence of an interpreter at a hearing – had a statistically significant influence on the likelihood of benefits being allowed. In 2003, GAO identified several limitations in its ability to analyze data related to race and ethnicity and issued recommendations to SSA. GAO noted there were data limitations because SSA significantly scaled back its collection of race and ethnicity data beginning in 1990.
- The racial inequity in the criminal justice system also directly impacts claimants' or beneficiaries' entitlements to SSI benefits. Benefits for SSI recipients who are incarcerated for more than 12 months are automatically terminated and must reapply for SSI when they return to the community.[101]

Intellectual & Developmental Disability

In 2017, there were approximately 7.4 million people with I/DD in the U.S., including approximately 5.3 million children and two million adults.[102] Individuals with intellectual disabilities have impaired cognitive ability caused by injury, genetic disorder, or neurological challenges.[103] Individuals with developmental disabilities have impaired mental, sensory, and/or physical ability and functional limitations in three or more areas (e.g., language, mobility, learning, and self-care), which likely require LTSS or HCBS.[104] It is important to note that many people considered to have a developmental disability have no cognitive impairment, oftentimes experiencing conditions such as blindness, spinal cord injury, cerebral palsy, etc.

Medicaid is vital because it is the primary LTSS payer for people with I/DD.[105] Nationwide, state and federal Medicaid funding provides over 75% of the funding for services for people with I/DD.[106] Medicaid provides funding for individuals with I/DD to live and work in the community and avoid more costly and segregated nursing homes and institutions.[107]

Research indicates that there are health disparities between people with I/DD and the general population, including poorer health outcomes and a higher prevalence of mental health diagnosis, and three or more chronic conditions. However, little is known about the extent of racial and ethnic health disparities among adults with I/DD. In a 2015 study analyzing survey datasets, the study found[108]:

- Black and Hispanic[109] adults with I/DD were significantly more likely to be in fair or poor health and mental health than white adults with I/DD
- Hispanic adults with I/DD were less likely to be insured all year than their Black and white counterparts.

A literature review done by the Administration on Community Living (ACL) in 2019, found that only two peer-reviewed studies analyzed the prevalence rates of I/DD in U.S. adults by race and ethnicity.[110] A Native American developmental disability needs assessment published in 2012 revealed that there are no national I/DD prevalence data specific to the American Indian/Alaska Native populations.[111] While studies on the prevalence of I/DD in adults are lacking, between 2000 and 2018, at least 35 studies were published reporting prevalence rates for I/DD in children. While children with I/DD are identifiable in several ongoing public health surveillance efforts, there is still a lack of data to inform best practices in addressing health equity for children and adults with I/DD.

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[99] Social Security: Racial Difference in Disability Decisions Warrants Further Investigation | U.S. GAO

[100] GAO-04-14 SSA Disability Decision Making: Additional Steps Needed to Ensure Accuracy and Fairness of Decisions at the Hearing Level

[101] Benefits after Incarceration (ssa.gov)

[102] Medicaid Services for People with Intellectual or Developmental Disabilities – Evolution of Addressing Service Needs and Preferences (macpac.gov)

[103] Improving Care for Individuals with ID/DD | UnitedHealthcare Community & State (uhccommunityandstate.com)

[104] Ibid.

[105] Medicaid Services for People with Intellectual or Developmental Disabilities – Evolution of Addressing Service Needs and Preferences (macpac.gov)

[106] Ibid.

[107] Medicaid & People With Disabilities | The Arc

[108] Disparities_brief_2015_1209.pdf (aucd.org)

[109] The authors of the study used the term "Latinos."

[110] ACL Literature Review

[111] Working Through the Data Conundrum: Identifying People with Intellectual and Developmental Disabilities in National Population Surveys (acl.gov)

Federal and State Actions

Federal

ACL is working to improve data collection to understand the lives and experiences of people with I/DD. ACL and federal partners worked with researchers, community partners, individuals with I/DD, and other stakeholders to develop two reports released in 2019. The first report, "Working Through the Data Conundrum: Identifying People with Intellectual and Developmental Disabilities in National Population Surveys," recommends new questions that could be used on national population-based surveys, such as the National Health Interview Survey, to identify individuals with I/DD. ACL is working with the National Center for Health Statistics at the CDC to test the recommended set of questions.

State

ACL's second report, "Enriching our Knowledge: State and Local Data to Inform Health Surveillance of the Population with Intellectual and Developmental Disabilities," explores how state-level data can be used to know more about the health status of the I/DD population. The report highlights the practices from states that have focused efforts on data collection and analysis that allow for the identification of people with I/DD in their datasets, and for expanding race and ethnicity information on people with I/DD with more granularity. The highlighted practices included:

- Collecting data on race, ethnicity, and language within the I/DD population to work toward culturally competent services.
- Hiring a data expert to create data linkages that allow the state's I/DD department to use Medicaid data to better understand the populations they serve.
- Developing a "data cube" to bring together administrative data from a variety of sources to identify trends by age, gender, race, disability, and more.
- Collecting data on people with I/DD who are not receiving state services, a population missing from administrative data sets.

Long-Term Services and Supports (LTSS)

LTSS refer to a broad range of medical, functional, and social services that are needed by individuals who have complex health needs due to aging, chronic illness, or disability.[112] The need for LTSS is generally measured by limitations in one's ability to perform activities of daily living (ADLs) such as eating, personal hygiene, dressing, and walking; and instrumental activities of daily living (IADLs), such as cooking, transportation, and managing finances; both of which allow individuals to live independently in their communities.[113] LTSS are delivered in a variety of settings, including home- and community-based settings (e.g., adult day services and personal care/homemaker services) and institutional care (e.g., intermediate care facilities for people with I/DD and nursing homes). Institutional LTSS is a mandatory Medicaid benefit, while HCBS is an optional Medicaid benefit.[114] Historically, due to the mandatory nature, LTSS expenditures were primarily spent on institutional care, but over the last several decades, states have sought to achieve a more equitable balance between the share of spending and use of services and supports delivered in home- and community-based settings relative to institutional care, a process often referred to as "LTSS rebalancing."[115] As of 2013, HCBS has represented a majority of LTSS expenditures and has remained higher than 50% since then, reaching 52% in 2019.[116]

Approximately 14 million individuals need LTSS in the United States today, including the ABD and I/DD populations.[117] Medicaid is important for individuals that currently use or will need LTSS because Medicaid serves as the largest payer for LTSS. According to a report from the Medicaid and CHIP Payment and Access Commission (MACPAC), "combined federal and state Medicaid expenditures for LTSS were $197 billion in 2020 – approximately 30 percent of total Medicaid spending."[118] The vast majority of individuals who utilize LTSS want to stay in their residence for as long as possible, making HCBS

LTSS federal and state Medicaid expenditures in 2016 were

$167 billion

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[112] Long-Term Services and Supports | UnitedHealthcare Community & State (uhccommunityandstate.com)

[113] Ibid.

[114] Mandatory & Optional Medicaid Benefits | Medicaid

[115] Rebalancing Toolkit (medicaid.gov)

[116] Medicaid Long Term Services and Supports Annual Expenditures Report: Federal Fiscal Year 2019 (mathematica.org)

[117] Overview of Long-Term Services and Supports

[118] EXHIBIT 20. Distribution of Medicaid Enrollment and Benefit Spending by Users and Non-Users of Long-Term Services and Supports : MACPAC

the more desirable choice for many individuals needing LTSS. However, racial disparities and sexual orientation discrimination are persistent across systems of LTSS and can keep individuals from receiving care in the setting of their choice. During the 2022 ADvancing States HCBS Conference, AARP and SAGE highlighted the following examples[119]:

- BIPOC individuals that use LTSS are often younger, have greater physical impairments, and are more likely to use nursing homes.
- Black and Hispanic adults are less likely to reside in high quality nursing homes.
- Nursing facilities serving higher proportions of people of color are more likely to have lower staffing levels and quality of care.
- Nearly half of respondents in a study on LGBTQ+ elders in long term care experienced mistreatment in a care facility from residents and staff.
- Half of older same-sex couples experience discrimination while applying for housing.
- At least 15% of LGBTQ+ Americans report postponing or avoiding medical treatment due to discrimination (this includes nearly 3 in 10 transgender individuals).
- For fear of discrimination, LGBTQ+ older adults are significantly less likely than other older adults to reach out to senior centers, meal programs, medical treatment, mental healthcare, and other essential aging services and programs.

The body of peer-reviewed research on racial and ethnic disparities in access to HCBS is small. More research is needed to better understand barriers to HCBS access for racial and ethnic minorities and to guide future policy to better address these disparities.

Federal and State Actions

Federal

In January 2021, Executive Order 13985, **Advancing Racial Equity and Support for Underserved Communities Through the Federal Government**, prioritized "a comprehensive approach to advancing equity for all, including people of color and others who have been historically underserved, marginalized, and adversely affected by persistent poverty and inequality." Individuals in underserved communities were defined as "Black, Latino, and Indigenous and Native American person, Asian Americans and Pacific Islanders and other persons of color; members of religious minorities; lesbian, gay, bisexual, transgender, and queer (LGBTQ+) person; persons with disabilities; persons who live in rural areas; and persons otherwise adversely affected by persistent poverty or inequality." Since the release of Executive Order 13985, we have seen various actions taken by the federal government to raise awareness of the need to address health inequities and build the needed infrastructure to address and advance health equity for the complex care population.

In line with Executive Order 13985, the CMS Office of Minority Health released the CMS Framework for Health Equity to address health disparities and systemic inequities in the delivery of care. The priorities outlined in the Health Equity plan will positively impact the complex care population served by Medicaid, especially the goal of expanding the collection, reporting, and analysis of standardized data by race, ethnicity, language, disability status, and other measures to better understand needs and targeted interventions.

Specifically, **Priority Number 5: Increase All Forms of Accessibility to Health Care Services and Coverage** highlights the need and prioritization of addressing the barriers individuals with disabilities face when "entering and navigating health care information and facilities."[120] To address these barriers, CMS is currently developing training for health care professionals on disability-competent care and raising awareness of programs for people with disabilities.[121]

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[119] Putting Older Adult Voices First: Addressing Barriers to HCBS for Racial/Ethnic & LGTQ+ Communities
[120] CMS Framework for Health Equity 2022–2032
[121] Ibid.

The table below summarizes some of the recent publications from the federal government related to health equity for LTSS beneficiaries.

Title	Health Equity Summary
HCBS Quality Measure Set	In July 2022, CMS released a set of nationally standardized quality measures for Medicaid-funded HCBS to promote more consistent use of quality measures and to “create more opportunities for CMS and states to have comparative quality data on HCBS programs.” The use of the measure set is currently voluntary, but CMS indicated that they plan to incorporate the use of the measure set into federal reporting requirements for specific authorities and programs for HCBS, including the Money Follows the Person program and future 1115 demonstrations that include HCBS. CMS emphasized using the measure set to promote equity by stratifying data by demographic characteristics, health status, and SDOH to identify health disparities among HCBS beneficiaries and identify where targeted interventions are needed to reduce inequities.
2020 Reauthorization of the Older Americans Act	Required that state and local departments of aging (i.e., state units on aging [SUAs] and area agencies on aging [AAAs]) conduct outreach to LGBTQ+ older people who need services in their communities.
CMS Issues Proposed Rule on Child and Adult Core Set Reporting	On August 22, 2022, CMS issued a proposed rule that would establish requirements for mandatory annual state reporting of three different quality measure sets beginning federal fiscal year 2024, including: - Core Set of Children’s Health Care Quality Measures for Medicaid and CHIP. - Behavioral Health Measures on the Core Set of Adult Health Care Quality Measures for Medicaid. - Core Sets of Health Home Quality Measures for Medicaid. One of the key highlights of this proposed rule is the introduction of phased-in stratification of all measures by race, ethnicity, sex, rural/urban status, disability, language, etc. over five years with states stratifying 25% of measures in Year 2, 50% of measures in Years 3 and 4, and 100% in Year 5 and beyond.

State

Many states recognize the importance of advancing health equity and have started building the needed infrastructure, such as developing dedicated health equity state offices and health equity plans, to develop targeted interventions. However, these plans do not always specifically detail how they will address the health disparities within the ABD, I/DD, or LTSS populations and instead focus on addressing individual social needs of the population as a whole.

Dually Eligible

Today, there are approximately 12 million individuals who are eligible for both Medicare and Medicaid – also known as dually eligible individuals.[122] Individuals generally become eligible for both Medicare and Medicaid because they are low-income, ABD, or have end-stage renal disease. All dual eligible beneficiaries receive some level of help with Medicare premiums or cost-sharing from their state Medicaid program, depending on the individual income and asset levels. Dual eligible beneficiaries can be “fully dual eligible” or “partially dual eligible.” Fully dual eligible beneficiaries receive Medicaid benefits and coverage for Medicare premiums and cost-sharing. Partially dually eligible individuals receive Medicare financial support, but no other Medicaid benefits. Individuals eligible for both programs face complex medical and social needs, have unmet behavioral and social health needs, and may have functional limitations. In many instances, this population must navigate an uncoordinated set of benefits, eligibility criteria, providers, and cost-sharing requirements. This fragmentation can lead to stress for the individual and their

Dual eligible beneficiaries can be “fully dual eligible” or “partially dual eligible.” Fully dual eligible beneficiaries receive Medicaid benefits and coverage for Medicare premiums and cost-sharing. Partially dually eligible individuals receive Medicare financial support, but no other Medicaid benefits.

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[122] Dually Eligible Beneficiaries: MACPAC

caregivers, poorer health outcomes, and individuals receiving incomplete care in inappropriate settings. In addition, dually eligible beneficiaries account for a disproportionate share of health care spending. In Medicare, dually eligible beneficiaries account for 19% of Medicare enrollees, but 34% of Medicare spending.[123] In Medicaid, dually eligible beneficiaries are 14% of Medicaid enrollees, but account for 30% of Medicaid spending.[124] According to the MACPAC, combined Medicare and Medicaid spending on dually eligible beneficiaries totaled $440.2 billion of which Medicaid accounted for $164.3 billion (37%) in 2019.[125]

According to Anne Tumlinson Innovations Advisory, when compared to Medicare-only beneficiaries, dual eligible beneficiaries[126]:

- Are 17% more likely to be female, 200% more likely to be Black or Hispanic, 573% more likely to be under the FPL, and 100% more likely to be unmarried;
- Have higher rates of chronic conditions such as congestive heart failure, chronic obstructive pulmonary disease, diabetes, and hypertension;
- Have higher rates of depression and serious mental illness; and
- Are four times more likely to experience food insecurity.

While it is well documented that dually eligible individuals generally have higher complex needs and experience with adverse SDOH compared to the general population and Medicare-only beneficiaries, the health disparities experienced by BIPOC, LGTBQ+, and other- underserved communities are under researched. Black and Hispanic Medicare beneficiaries are overrepresented in the dually eligible population, highlighting the need for the federal government and states to examine the reason for the overrepresentation and consider the impact of systemic racism as well as cultural differences that shape beneficiaries' experiences when navigating the healthcare system.

Federal and State Actions

Federal

The HHS Office of Inspector General published a study titled "Inaccuracies in Medicare's Race and Ethnicity Data Hinder the Ability to Assess Health Disparities." The report highlighted that the ability to assess health disparities hinges on the quality of the underlying race and ethnicity data. The report assessed the accuracy of Medicare's enrollment race and ethnicity data for different groups by comparing them to self-reported data for a subset of beneficiaries who reside in nursing homes. The report found that[127]:

- Race and ethnicity data that are self-reported are considered the most accurate.
- Medicare's enrollment race and ethnicity data are less accurate for some groups, particularly for beneficiaries identified as American Indian/Alaska Native, Asian American and Pacific Islander, or Hispanic.
- Limited race and ethnicity categories and missing information contribute to inaccuracies in the enrollment data.
- Medicare's enrollment data on race and ethnicity are inconsistent with federal data collection standards, which inhibits the work of identifying and improving health disparities within the Medicare population.

The report recommended that CMS: "(1) develop its own source of race and ethnicity data, (2) use self-reported race and ethnicity information to improve data for current beneficiaries, (3) develop a process to ensure that the data are as standardized as possible, and (4) educate beneficiaries about CMS's efforts to improve the race and ethnicity information."

Recently, CMS both expanded the definition of 'primarily health related' to allow supplemental benefits to include things that are more LTSS like and additionally began allowing plans to offer SDOH related benefits for the first time specifically to individuals with chronic conditions (known as Special Supplemental Benefits for the Chronically Ill or SSBCI). Through the flexibilities permissible under the Medicare Advantage (MA) Value-Based Insurance Design (VBID) model which allows MA plans to offer innovative and high-value benefits to low-income populations combined with SSBCI, MA plans began offering benefits to members not typically available in Medicare or Medicaid, including healthy food, non-medical transportation, cash rebate cards, utilities, and Rx cost-share coverage. Some MA plans have started utilizing SSBCI to holistically serve beneficiaries with complex care needs and address their unmet needs.

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[123] Dually Eligible Beneficiaries: MACPAC

[124] Ibid.

[125] Ibid.

[126] A-Profile-of-Medicare-Medicaid-Dual-Beneficiaries.pdf (atiadvisory.com)

[127] Inaccuracies in Medicare's Race and Ethnicity Data Hinder the Ability To Assess Health Disparities

The table below summarizes some of the recent publications from the federal government related to health equity for the dually eligible population.

Title	Health Equity Summary
Medicare Program; Contract Year 2023 Policy and Technical Changes to the Medicare Advantage and Medicare Prescription Drug Benefit Programs, 87 Fed. Reg. 1842	Over the past several years, federal and state policymakers have increasingly prioritized Medicare-Medicaid integration for dual eligible special needs plans (D-SNPs). This proposed rule introduced changes to improve integration. One of the changes related to health equity included requiring all Special Needs Plans, including D-SNPs, to incorporate questions into their health risk assessments that ask about enrollees' access to housing, food, and transportation. These questions allow D-SNPs to discuss identified risks and unmet needs and develop expanded supplemental benefits to address those needs. At both state and national levels, policymakers can also choose to collect this data from D-SNPs to study and address the health-related social needs of D-SNP enrollees, and the needs of dually eligible populations more broadly.
CMS RFI on Medicare Advantage	On August 1, 2022, CMS released an RFI seeking feedback on ways to strengthen MA in ways that align with the CMS Strategic Pillars and Vision for Medicare. The Vision for Medicare focuses on Medicare beneficiaries receiving "equitable, high quality, and whole-person care that is affordable and sustainable." CMS was seeking feedback regarding how they can ensure all MA enrollees receive the care they need, especially for individuals in underserved communities; and examples of programs and innovations that can advance health equity in MA. Additionally, they asked about the socioeconomic data MA plans leverage to better understand enrollees, inform care delivery, and establish partnerships with local community-based organizations.

State

Many states are working on developing programs that help their dually eligible population navigate their care, improve their health outcomes, and address health disparities. States are increasingly using their D-SNP State Medicaid Agency Contract (SMAC) to integrate certain Medicare and Medicaid programmatic elements by blending care management and administrative processes and policies into one unified delivery system. While states offering more integrated products will likely improve health outcomes and experience for dually eligible beneficiaries in general, there is need for continued focus on data and targeted interventions to ensure health equity among dually eligible individuals.

Medicaid's Unique Role in Defining Health

As noted throughout this report, for over 81 million individuals Medicaid is the source of coverage that provides access to needed physical, behavioral and social care. Medicaid programs across the country have a powerful ability to influence health through program design levers that provide complete and trusted data, measure and report outcomes, prioritize delivery system reforms and seek to meet the unique needs of populations.

At UnitedHealthcare, we are committed to making the health care system work better for everyone by addressing the disparities that prevent people from living their healthiest lives. Regardless of race, gender, sexual orientation, gender identity, geography, disability status, and all other demographic factors, the communities and individuals we serve – particularly those in our Medicaid, CHIP and Special Needs Plans—deserve the opportunity, support, and access necessary to achieve their optimal health and wellness.