CMS wants to empower all individuals to efficiently navigate the healthcare system and access comprehensive healthcare. We are interested in receiving public comment on personal perspectives and experiences, including narrative anecdotes, describing challenges individuals currently face in understanding, choosing, accessing, paying for, or utilizing healthcare services (including medication) across CMS programs.

Response 1: Challenges Individuals Face in Accessing Services; Enrollment

Medicaid and CHIP-eligible individuals and enrollees, particularly individuals who are Black, Indigenous, and People of Color (BIPOC), Lesbian, Gay, Bisexual, Transgender, Queer, or Intersex (LGBTQI+), Limited English Proficient (LEP), and people with disabilities (PWD), continue to experience difficulty accessing many aspects of the programs.

At the application stage, people who otherwise qualify for Medicaid and CHIP face barriers to enrollment, including lengthy, inaccessible forms, lack of understanding about eligibility, and poor outreach to eligible communities. Applications may not be available in the primary language of the applicant or applicants’ parents/guardians, and may not include taglines that inform the applicant of their right to receive language services. Other administrative burdens, such as requiring duplicative information from applicants, relying on poorly-designed websites or call centers with lengthy wait times, and communicating with applicants only by mail, reduce access for individuals who are otherwise Medicaid and CHIP-eligible.

Current Medicaid and CHIP enrollees face barriers in accessing services to which they are entitled to under federal law. Many programs and providers fail to provide culturally,
linguistically appropriate services, including language access services required under Title VI. People with disabilities experience issues with physical inaccessibility in hospitals and provider offices, as well as inequity in use of assistive communication devices. Long wait times to see providers, distance of providers, and inaccurate provider networks frequently leave enrollees with inadequate and inaccessible medical care, particularly in the most underserved areas. PWD face unreasonably long wait times to access Home and Community Based Services, making these medically necessary services effectively out of reach.

Current enrollees experience challenges with churn or disenrollment at redetermination due to avoidable administrative burdens. We are particularly concerned with heightened disenrollment at the end of the PHE, which could result in millions of eligible individuals and families losing access to Medicaid and CHIP and a disproportionate effect on communities of color. Preliminary studies have shown that Latinx individuals, PWD, and LEP individuals face the highest risk of disenrollment from Medicaid and CHIP.

Finally, we want to highlight the particular issues faced by enrollees seeking to access reproductive and sexual health services, including abortion, and gender-affirming care. State laws limiting or banning this medically necessary care disproportionately affect Medicaid and CHIP enrollees, who cannot otherwise afford to pay out of pocket. The Medicaid Act and Section 1557 of the Affordable Care Act require coverage of these services.

Response 2: Recommendations for How CMS Can Address These Challenges

CMS must monitor state Medicaid and CHIP applications to ensure that they are accessible, available, and streamlined. CMS must ensure that applications are available online in an accessible format and included within each state and federally-facilitated marketplace application. CMS can support states by providing language access resources and technical support, assisting each state in creating a language access plan, and by enforcing language access requirements of Title VI and Section 1557. CMS can also provide resources and toolkits for states seeking to improve outreach to Medicaid- and CHIP-eligible individuals and families who are LEP.

Churn harms Medicaid and CHIP enrollees and results in a high administrative cost to states. To prevent churn and disenrollment of eligible individuals, CMS must ensure that states follow its regulations regarding zero income attestation, use of integrated eligibility tools, and streamlined eligibility requirements. (See NHeLP’s Comments on CMS Request for Information on Access to Coverage and Care in Medicaid & CHIP.) CMS can promote additional policies to reduce churn, such as requiring twelve months of continuous coverage, automatically renewing coverage for individuals unlikely to experience a change.
in circumstances – such as SSI recipients – and allowing states to use federal tax filings to certify eligibility.

We strongly recommend that CMS adopt robust demographic data collection throughout its programs and develop core measures to monitor program access. Without detailed information on who accesses programs and how programs are accessed, CMS cannot ensure equitable service delivery. While individual states could be responsible for collecting and analyzing state-level data to evaluate compliance with national standards set by CMS, we urge CMS to take a strong role in monitoring states’ efforts and enforcing compliance if the data reveals access problems. Standardized measures are needed to ensure that standards do not vary too widely from one state to another, and that oversight by CMS is not fragmented. We recommend that CMS measure all metrics at the county or service area level so that it and the states can best monitor local access patterns and identify gaps at the local level. Demographic data collection is discussed in more detail in our response to Question 3. For our recommendations on core access measures for Medicaid and CHIP, please see our Proposed Metrics.

Finally, we would like to highlight steps that CMS can take to preserve access to reproductive and sexual health care, including abortion, and gender affirming care. CMS should reiterate states’ legal obligations to cover all abortions within the Hyde amendment exceptions including different service types (e.g., medication, procedural, and surgical) and delivery formats (in person; telehealth; mailing or delivery) required within Hyde Amendment exceptions and ensure that medication abortion is covered by mail. CMS should issue guidance consistent with the requirements of Section 1557 of the Affordable Care Act that clarifies the medical necessity of gender-affirming care.

NHeLP’s comments on the prior Request for Information on Access to Coverage and Care in Medicaid and CHIP further discuss these issues. On the above topic, we request incorporation of those comments by reference.

**Topic 2 of 4: Provider Experiences**

**CMS wants to better understand the factors impacting provider well-being and learn more about the distribution of the healthcare workforce.** We are particularly interested in understanding the greatest challenges for healthcare workers in meeting the needs of their patients, and the impact of CMS policies, documentation and reporting requirements, operations, or communications on provider well-being and retention.

**Response 1: Factors that Impact Provider Wellbeing**

No response given.
Response 2: Recommendations for CMS Policy and Program Initiatives to Support Provider Wellbeing

No response given.

Topic 3 of 4: Advancing Health Equity

CMS wants to further advance health equity across our programs by identifying and promoting policies, programs, and practices that may help eliminate health disparities. We want to better understand individual and community-level burdens, health-related social needs (such as food insecurity and inadequate or unstable housing), and recommended strategies to address health inequities, including opportunities to address social determinants of health and burdens impairing access to comprehensive quality care.

Response 1: CMS Policies That Can Help Advance Health Equity

CMS should do more to audit states’ eligibility determination systems and enforce the requirement that eligibility policies and procedures be “consistent with simplicity of administration and the best interests of the applicant or beneficiary.” 42 C.F.R. § 435.02. Many state systems rely heavily on automated processes, centralized document processing, and separated workflows that are rarely set up for auditing, error reporting, or tracking disparate impact. Further, Medicaid and CHIP eligibility systems, including the systems themselves and associated document management processes, are notorious for losing documents and repeatedly asking for the same or unnecessary documents or information. For example, Tennessee’s renewal packet is nearly 100 pages and they are likely not alone. Renewal paperwork should not ask repeatedly for the same information, request unnecessary information, fail to meet plain language requirements, or otherwise be confusing. Application processes that require additional information must avoid similar issues.

CMS must also do all it can to reinforce requirements for effective communication, particularly for PWD, LEP individuals, and older adults in the eligibility and redetermination processes. Too often, applicants and beneficiaries in these protected groups lose eligibility because states do not provide the necessary communication assistance in what can be complicated application and redetermination processes. Complicated eligibility systems, insufficient notices, reliance on technology, and complicated workflow processes can mean eligibility workers are rarely able to fully and helpfully answer an applicant or beneficiary’s questions. This violates the requirement that a State provide application assistance and ensure the accessibility of their eligibility processes. CMS should offer clearer guidance on
and conduct active enforcement to ensure the appropriate level of assistance to meet Medicaid and CHIP program, non-discrimination, and Due Process Clause requirements.

CMS can support states by providing better language access infrastructure and resources for outreach to PWD and local LEP communities. CMS should require each state to provide a language access plan as part of their state plan for Medicaid and a broader communication plan, which CMS should carefully review and require states to publicly post and update regularly. We request that our comments on language access, accessibility for people with disabilities, and the provision of auxiliary aids in response to the Proposed Rule on Nondiscrimination in Health Programs and Activities be incorporated here by reference.

CMS should ensure access to Long Term Services and Supports (LTSS) and Home and Community Based Services (HCBS) by developing metrics to evaluate: if needed care is being prescribed; if provider capacity is sufficient; what proportion of prescribed hours is actually being filled (especially due to provider shortages); the number of providers identified during the planning process/provider change period who were actually willing to accept the beneficiary for all needed services; and how assessed “need” is being inappropriately influenced, for example, basing need on extraordinary supports from friends or family, or unreasonable expectations on service recipients themselves. As with other metrics, CMS must hold state programs to account by taking an active role in enforcement.

Finally, as abortion access is rapidly decreasing, CMS should focus on leveraging its authority to ensure states fulfill their legal obligation to provide abortion coverage as required by the Hyde amendment, which limits the use of federal funds for abortion coverage to cases of rape, incest, and life endangerment. The Hyde amendment often functions as a de facto ban and disproportionately impacts BIPOC; LGBTQ+ people; young people; immigrants; and PWD. It deepens already dire intergenerational health inequities. Particularly following the Supreme Court’s decision in the recent Dobbs v. Jackson Women’s Health Organization, rectifying states’ failure to adequately cover abortions even in these limited cases is necessary to achieve the administration’s public commitments to addressing racial, gender, and other health inequities. CMS should reiterate states’ legal obligations to cover all abortions within the Hyde amendment exceptions including different service types (e.g., medication, procedural, and surgical) and delivery formats (in person; telehealth; mailing or delivery) required within Hyde Amendment exceptions.

Response 2: Impact on Underserved Communities When Providers Leave the Community or are Removed from Participation in CMS programs

Lack of adequate providers in Medicaid and CHIP plans and MCO networks further burdens underserved communities, who already experience higher wait times and fewer
care options than average. When communities and insurer networks lose providers, BIPOC, LEP individuals, LGBTQI+ individuals, and PWD are most impacted. For example, a study in Virginia found that areas with a larger Latinx population have a lower share of primary care providers that accept Medicaid and CHIP as compared to the rest of the state.

To address this issue, we strongly recommend that CMS set a national core set of access to care measures and enforce those standards to ensure reasonable promptness of services. We urge CMS to quickly finalize a strong rule on access that measures access not only in terms of potential, but also in terms of realized access. In Medicaid and CHIP, salient indicators of potential access include: provider participation and provider location. Any measures of provider participation must account for the expected utilization of beneficiaries in the service area relative to: the specialization, experience, and expertise of participating providers; the extent to which providers are accepting new patients; and the scope of services provided by participating providers and facilities, including any limitations on service provision pursuant to religious or moral objections. Measures should also account for meaningful participation, as researchers have consistently done when they study Medicaid and CHIP payments and provider participation, for example defining a participating provider as one who sees a certain number of patients or submits a certain amount of claims per year. Measures of provider location must account for the expected utilization of beneficiaries in the service area relative to: the distance of participating providers and facilities from beneficiaries’ homes and workplaces; the means of transportation used by beneficiaries relative to provider sites (i.e., if most beneficiaries rely on public transit, are participating providers proximate to major transit lines); and the extent of transportation assistance offered by the state.

Salient measures of realized access include: the time it takes to schedule an appointment; the amount of time beneficiaries spend waiting to see a provider after the time of a scheduled appointment; the amount, duration, and scope of services received versus prescribed; the number of referrals received versus those made; and the proportion of enrollees, including children, who receive recommended screenings and immunizations. We emphasize that measures of realized access are particularly important since too often, measures of potential access are not sufficiently nuanced to ensure that enrollees have access to all covered benefits. Measures that only count the numbers and locations of providers, for example, fail to account for whether providers are obligated to provide all covered services that fall within the scope of practice of their provider license. Enrollees may not be able to access needed care due to providers’ unwillingness or protected refusal rights to provide a covered service. For example, if a state provides geographic access to OB/GYNs who provide prenatal care, but it does not contract with any providers who provide counseling and prescriptions for family planning services in its service area, enrollees will not have adequate access to those services. Similarly, measures of potential access frequently do not account for the sub-specialization, particular expertise, or scope-
of-practice of providers. For the parent of a child Medicaid beneficiary with leukemia, knowing that the state has contracts with many oncologists is little help if the state cannot provide her child access to a pediatric oncologist with experience treating childhood leukemia.

We emphasize that setting rigorous standards for access must be paired with a robust plan for ongoing monitoring and enforcement. Experience from both federal and state programs has demonstrated that a layered approach to network adequacy – one that accounts for both potential and realized measures of access, and that employs multiple strategies to monitor and enforce compliance with network standards – is the most effective way to ensure that people can actually get the right care in the right place at the right time. Moreover, all stakeholders benefit when the standards are clear and easy to measure. Specific standards are important so that beneficiaries and advocates know whether access problems they experience warrant a complaint.

Response 3: Recommendations for How CMS Can Better Support & Promote Health Equity

While the existence of health disparities has been well documented, the complex factors that contribute to and mitigate against them are still not fully understood. In part, this is due to a lack of high quality, large scale, and easily available demographic data on the populations participating in various programs. Even where this information is collected, data on smaller racial and ethnic groups is often not extensive enough to lend itself to meaningful analysis. Similarly, data is often not available for intersecting sub-populations that might experience multiple barriers to access.

We urge CMS to require disaggregated demographic data collection in all federal health program and activities, those conducted by the federal agencies themselves and those funded by the federal government. The demographic data should include race, ethnicity, preferred language, sex, gender identity, sexual orientation, intersex status, disability status, and age.

We strongly recommend that CMS require programs to collect demographic information of participants on program applications and ensure that information remains available to be shared with necessary entities. For example, demographic information on Medicaid and CHIP applicants should be shared with managed care entities and providers using secure and confidential procedures defined by CMS. Information sharing lessens the burden on applicants, enrollees, and entities by reducing the number of times, and administrative cost, of collecting duplicative information. It also enables insurers, providers, and other entities to plan for accessibility needs of enrollees, including language access and disability accommodations, as well as ensure culturally competent care.
CMS should adopt standardized categories and definitions for demographic information collected by programs. Racial, ethnic and preferred language data should be collected at a granular level to allow for disaggregation, particularly for Asian Americans, Native Hawaiians and Pacific Islanders (AANHPI), Latinx and indigenous populations, and Middle Eastern and Northern African (MENA) populations. CMS should adopt the minimum standards for AANHPI as recommended by NCAPA and for MENA the recommendations from ACCESS. Sexual orientation, and gender identity, and variations in sex characteristics (SOGISC) data should build on the questions employed by other federal agencies, and the recommendations from the National Academies of Sciences, Engineering and Medicine in their 2022 report *Measuring Sex, Gender Identity, and Sexual Orientation*. Standardized disability questions should identify people with functional limitations associated with certain cognitive, emotional, or learning impairments and use the American Community Survey questions about functional limitations as a starting point.

Collection of demographic data is important for planning purposes, particularly with regards to people with disabilities and limited English proficiency. For example, collecting functional limitation information on applications will help providers plan ahead for patients’ need for accommodations during clinical visits and hospitalizations, hopefully increasing the likelihood that accommodations needed for equally effective healthcare will be provided in a timely and consistent way. Collecting language data of individuals (and their parents and guardians for those who are minors or incapacitated) will help ensure various entities have effective language access policies and procedures in place to meet their needs.

Additionally, CMS must ensure that data collected is maintained safely and securely by the appropriate entities. Strict standards must be adopted to ensure that data cannot be used for negative actions such as immigration or law enforcement, redlining or targeting of specific groups. We encourage CMS to ensure that the privacy protections applied to demographic data comply with the privacy and security standards set forth in ACA Section 3101, which built upon the privacy protections required by HIPAA. Individuals should be made aware of their privacy protections and rights and have a clear understanding of why demographic data is being collected and who will have access to which forms of information. CMS should also consider what protections can be put in place about how such data is used for research and other purposes that lead to the development of analyses, tools, and algorithms that may ultimately be used to deny services or otherwise make decisions about the populations from whom the data has been collected.
Response 1: Impact of PHE Waivers on Providers, Patients, Suppliers, and Other Stakeholders

Many of the flexibilities created during the PHE decreased barriers to health care for Medicaid and CHIP enrollees and those eligible for Medicaid and CHIP.

For those applying for Medicaid and CHIP, changes to enrollment processing enabled eligible individuals to access health care despite the ongoing pandemic. States have streamlined Medicaid and CHIP enrollment in the past several years by expanding presumptive eligibility, adopting 12-month continuous eligibility, extending the opportunity to respond to verify or provide information, allowing self-attestation, extending call center hours, and expediting processing of applications. These actions include proven solutions to reduce barriers and facilitate enrollment for eligible individuals.

PHE flexibilities around prior authorization decreased the administrative burden for individuals seeking access to services such as medical equipment and supplies, direct support professionals (DSP), and certain prescription drugs. Changes to HCBS payment rates, retention bonuses, and PPE supplies made an enormous difference for DSP and those relying on DSP. Reimbursements for family caregivers made it possible for individuals to obtain needed support, especially given the ongoing provider shortage.

Finally, expanding telehealth had a profound impact on access to care, particularly for enrollees who live in rural areas or are members of underserved communities. In addition, telehealth has facilitated abortion access for enrollees in areas where providers are sparse. CMS can do more to reduce the burden on low-income, rural, and other underserved enrollees by ensuring equal access to telehealth across populations and geographic locations, providing resources for connectivity and technology, and issue guidance on providing abortion and other reproductive health care via telehealth.
Response 2: Recommendations for How CMS Can Focus on Addressing Health Disparities Exacerbated during the PHE

CMS can address health disparities that widened during the COVID pandemic and prepare for the next PHE by instituting broad demographic data collection across its programs, using that data to identify disparities and create solutions, creating core measures of access, focusing on quality standards and network adequacy, and fully enforcing existing and future requirements.

As discussed above, demographic data collection can enable CMS to obtain information on health disparities at the community and program level, track and identify barriers to health care, and monitor programs for health equity. Especially during a pandemic, CMS needs demographic data to be able to understand who is more impacted, who receives services, and where gaps exist in access. Core measures of access, network adequacy, and quality of care may also lessen the burden of individuals seeking adequate health care over time. We urge CMS to quickly adopt and implement standardized demographic data collection requirements, along with the Proposed Rule on Mandatory Medicaid and CHIP Core Set Reporting and the Proposed Rule on Streamlining the Medicaid, CHIP, and BHP Application, Eligibility Determination, Enrollment, and Renewal Processes. Please see our answers to Question 3, above, and we request to incorporate by reference our comments on these Proposed Rules for additional consideration here.

Some CMS actions taken to address the PHE unfortunately did exacerbate health disparities in underserved communities. Crisis standards of care deprioritized and further stigmatized older adults and PWD. An intense focus on nursing facilities and institutional placements benefitted overworked providers, but did not place nearly as much emphasis on people receiving those services and the need to support community placements. Policy choices about vaccine distribution and testing failed to adequately engage BIPOC communities and PWD, especially those with chronic conditions. As a result, these communities experienced higher rates of infection, hospitalization, and death.

NHeLP has written extensively about the waivers and flexibilities that have tremendously helped alleviate administrative burdens and should remain in effect after the end of the PHE. Flexibilities in enrollment verification, service delivery, and renewal processes facilitate access for all eligible individuals. Telehealth access has made a profound difference in access for enrollees, particularly for behavioral and mental health care and for low-income and underserved populations. For NHeLP’s detailed recommendations on please see our Medicaid Principles on Telehealth. However, as reiterated throughout our comments, CMS must track access to care, including telehealth care, to more thoroughly understand the impact of each program on particular communities.