



♥ Ensuring a Place at the Table for Every Family

## Comments of National PLACE on US DHHS Strategic Plan 2022-2026

### Introduction

The National Center for Parent Leadership, Advocacy, and Community Empowerment (National PLACE) is pleased to provide our comments and recommendations on the US Department of Health and Human Services (HHS) Strategic Plan. National PLACE is a coalition of 70 national, state, and local parent-led, family-serving non-profits who are committed to enhancing the voice and impact of diverse families and family-led organizations at decision-making tables at the individual, program, and systems levels. Our members include federally-funded Parent Centers (US Department of Education), Family to Family Health Information Centers (US DHHS HRSA Maternal and Child Health Bureau), and Statewide Family Networks (US DHHS SAMHSA), as well as National Federation of Families (for Children's Mental Health) and Parent to Parent USA affiliates, among others.

Overall we support the strategic plan's current strategic goals and objectives. Our primary recommendation is to enhance the role of stakeholders, including people with lived experience who are the intended beneficiaries of HHS programs, supports, and services, and especially those representing the most un/underserved individuals and families and who face the poorest outcomes across domains, in identifying strengths and weaknesses of current systems and programs, recommending and planning for improvement, implementing improvement plans, evaluating impact of those plans, and ensuring continuous quality improvement. As organizations whose Boards include a majority of parents of children, youth and young adults ages birth through 26, and who are staffed by diverse individuals with lived experience who have navigated and advocated within multiple systems, including those addressed by the US Department of Health and Human Services (HHS) strategic plan, we know that families and the family-led organizations that work with them have on-the-ground insights into programs and systems that cannot be matched by anyone else at the table.

The strategic plan must prioritize the engagement – with needed supports – of representatives of this critical constituency, especially those who currently have the least access to high quality supports, services, and programs. The strategic plan must explicitly focus on recognizing and strengthening the role of families as decision-makers for their children and as partners with professionals, providers, and policymakers and providing the needed resources to family-led organizations to enable us to reach, inform, engage, and support families from the full range of diverse backgrounds, including based on race, ethnicity, language, disability or special healthcare needs, immigrant status, gender, sexual orientation, gender identity, geography, involvement in the child welfare or juvenile justice systems, etc.

Too often the role of families is given mere lip-service, and families are not adequately prepared or supported to participate as equal and powerful partners with professionals. In many other instances, one or two parents are invited to participate but can only speak to their own experience because they are not affiliated with a family-led organization that speaks with thousands of families representing a wide variety of experiences and perspectives. In addition, when individual families are selected by systems to participate in systems-improvement efforts, without the support of family-led organizations, they may feel intimidated to speak up, particularly when they disagree with professionals. This is especially true for un/underserved families who have faced discrimination and who may face explicit or implicit bias from others at systems improvement tables.

Further, our members include family-led organizations in states, the District of Columbia, territories, urban centers, and rural and tribal communities. It is critical that the strategic plan refer not only to states but also to territories, jurisdictions (such as DC), tribal nations, etc., not only in those objectives where there is a specific mention of some of these other jurisdictions but throughout the plan.

### **Comments on Specific Strategic, Strategic Objectives, Strategies, and Activities**

#### ***Strategic Goal 1: Protect and Strengthen Equitable Access to High Quality and Affordable Healthcare***

National PLACE supports Strategic Goal 1 and its emphasis on *equitable access to high quality and affordable* healthcare. Our specific comments on each Strategic Objective follow.

#### ***Strategic Objective 1.1: Increase choice, affordability, and enrollment in high-quality healthcare coverage.***

National PLACE supports Strategic Objective 1.1. The families we support too often face limited choices, a lack of affordability, and barriers to enrollment in healthcare coverage that does not always provide access to high quality healthcare. National PLACE also endorses each of the identified strategies, including to promote available and affordable healthcare coverage to improve health outcomes in our communities; empower consumers with choices for high quality healthcare coverage; and leverage knowledge and partnerships to increase health coverage enrollment. In particular, we strongly support outreach efforts to inform eligible individuals of affordable healthcare insurance options and related cost-saving opportunities, including premium and cost-sharing assistance and note that funding entities staffed by individuals who have learned about these options and opportunities such as family-led organizations is an effective and efficient approach.

National PLACE also endorses improving transparency of choice and access to available health coverage options, including Medicare, Medicaid, and Marketplace plans, for all consumers seeking coverage or searching for alternatives; promoting partnerships and collaborations with states to provide and monitor equitable and timely access to Medicaid and Children's Health Insurance Program (CHIP) providers and services; and facilitation of enhanced understanding of eligibility, improved screening, and health insurance literacy to bolster enrollment and coverage of underserved populations. Again, funding entities staffed by individuals who have learned about these options and opportunities such as family-led organizations is an effective and efficient approach.

Finally, National PLACE agrees with the importance of supporting states, tribes, territories, grantees, faith-based organizations, and other federal award recipients through technical assistance and capacity building to expand pathways to high-quality healthcare coverage for all populations; building the

capacity of organizations to navigate the changing healthcare landscape to better support their clients to access and use their health coverage to improve health outcomes; monitoring and assessment to improve enrollment and retention of eligible individuals in comprehensive public and private coverage, including Medicaid and the Children's Health Insurance Program (CHIP), Qualified Health Plans through an Exchange, and other high-quality comprehensive private insurance; and supporting research, including the application of findings and lessons learned, related to the cost effectiveness and affordability of insurance coverage for diverse populations.

With regard to these strategic activities, National PLACE notes research regarding the value add, effectiveness and efficiency of strategies to enroll, keep enrolled, and access services under health coverage using trained parents in Texas and funding of a family-led organization in Rhode Island.

In Rhode Island, the state Department of Health funded the Rhode Island Parent Information Network (the RI Parent Training and Information Center and Family to Family Health Information Center) to house Family Resource Specialists (trained parents of children and youth with special healthcare needs) at pediatric practices to provide support to families of children with and without disabilities and special healthcare needs via the Pediatric Practice Enhancement Project (PPEP) with State Implementation Grant funding from HHS Maternal and Child Health Bureau (MCHB). A study of the impact of this model demonstrated that families more appropriately used primary care services, leading to higher average visits per child with lower claims per visit, and that overall the claims per visit for resource intensive services were lower, suggesting that this model increases utilization of primary/ preventive care and that this increased utilization of these services may decrease utilization of costlier services. Utilization and costs were lower for inpatient admissions, and costs lower for emergency visits. In addition to these positive impacts on use of primary/preventive care and use and costs for inpatient admissions and emergency room visits, families served by PPEP reported greater understanding and satisfaction regarding the health care service system, a sense of empowerment, and enhanced knowledge of available supports. The program also enhanced provider satisfaction. Reports from participating physicians indicated that the program enhanced their efficiency and knowledge of the special needs delivery system and reduced scheduling delays and family waiting time for services. Unfortunately, once the grant funding ended, despite the demonstrated benefits of the program in reducing costs and increasing access and family and provider satisfaction, the program ended in most practices. We have included several articles on this effective, efficient approach.

A randomized trial study in Texas found that trained parents of children with special healthcare needs (CSHCN), known as Parent Mentors, insured more uninsured children faster than traditional Medicaid/CHIP outreach, improved children's access to services including primary, dental, and specialty care, reduced unmet needs and out-of-pocket costs, improved parental satisfaction, enhanced the quality of well-child care, eliminated disparities in the Texas Medicaid program, and saved thousands of dollars per child (the cost of Parent Mentors was approximately \$53/child/month, and saved \$6,045.22/insured child). Parent Mentors also helped families renew coverage faster. The study, led by Medica Research Institute Distinguished Chair in Health Policy Research Glenn Flores, is the first to assess the effectiveness of Parent Mentors in insuring uninsured minority children. Parent Mentors were able to leverage their relevant experience, along with additional training, to assist, counsel, and support other parents, including assisting families with insurance applications, retaining coverage, medical homes, and social needs. The research team previously found that Parent Mentors were effective in improving outcomes for minority asthmatic children; this study was the first to evaluate their effectiveness in covering uninsured children by helping families with insurance applications, retaining coverage, medical homes, and social needs.

In particular, Parent Mentors were found to be more effective than traditional Medicaid/CHIP methods in insuring children (95% vs. 68%); achieving faster coverage (median of 62 days vs. 140 days); achieving high parental satisfaction (84% vs. 62%) and quality of well-child care (quality rating 8.9 vs. 8.6); and renewing coverage (85% vs. 60%). The Parent Mentor group was less likely to have no primary care provider (15% vs. 39%); encounter problems getting specialty care (11% vs. 46%); have unmet preventive care needs (4% vs. 22%); have unmet dental care needs (18% vs. 31%); experience dissatisfaction with doctors (6% vs. 16%); and need additional income for medical expenses (6% vs. 13%). Two years after the study's conclusion, 100% of Parent Mentor children were insured versus 76% of control children. Parent Mentors cost \$53.05 per child per month, but saved \$6,045.22 per child per year. These savings were realized from less costly emergency department visits, hospitalizations, and ICU stays among the children, and lower wage losses and other costs for caring for sick children for parents. Based on the cost savings documented in this study, estimates indicate that national implementation of Parent Mentor interventions to insure all Medicaid/CHIP eligible uninsured children could potentially save our nation \$17-\$20 billion. As the study's author noted, "Parent Mentors are successful, in great part, because they are interactive, provide social support, and connect parents of uninsured children from similar racial and ethnic backgrounds." Disturbingly, these results have not led to significant implementation of this approach in Texas or any other state. Read more about this study at [Parent mentors insure more uninsured children, improve access, eliminate disparities \(medicalxpress.com\)](http://parentmentors.org/parent-mentors-insure-more-uninsured-children-improve-access-eliminate-disparities-medicalxpress.com).

*Strategic Objective 1.2: Reduce costs, improve quality of healthcare services, and ensure access to safe medical devices and drugs.*

National PLACE endorses this Strategic Objective, particularly its focus on improving quality of healthcare services. However, we strongly encourage HHS to reorder the components of this Strategic Objective to start with improving quality of healthcare services, followed by ensuring access to safe medical devices and drugs, and ending with reducing costs. Reducing costs is a laudable objective, but it should come after quality improvement and access to safe interventions.

National PLACE also strongly supports this objective's focus on ensuring implementation of the National Standards for Culturally and Linguistically Appropriate Services in Health and Healthcare.

In terms of particular activities under this Strategic Objective, National PLACE endorses engagement of stakeholders from underserved populations to provide opportunities for input to inform program and policy efforts to improve healthcare quality and recommends that this and all future references to stakeholders explicitly mention individuals with lived experience and their families as well as the organizations that are led and staffed by individuals with lived experience and their families such as Parent Centers, F2Fs, SFNs, and Federation of Families and Parent to Parent affiliates.

National PLACE also supports the activity to engage in tribal and Urban Indian Organization consultation and confer on what improving quality health care services means for tribal communities, who are among the most un/underserved populations and whose members have the least access and the poorest outcomes in many domains.

National PLACE supports the activity to partner with states and external quality measure development experts to define and encourage use of a core set of metrics to measure provider effectiveness in Medicaid, the Children's Health Insurance Program (CHIP), and pay-for-performance programs, including reliable metrics of access to care, gaps in care, disparities, health equity, and achieving positive

outcomes for all populations. However, we recommend explicit inclusion of language regarding stakeholder engagement, specifically including a focus on engagement of un/underserved individuals and their families and the family-led organizations that support them and who have insights from tens of thousands of families from diverse backgrounds reflecting a variety of diverse experiences.

In the same vein, National PLACE endorses the support for research, including the application of findings and lessons learned, related to the cost effectiveness and affordability of insurance coverage for diverse populations, but again recommends explicit inclusion of language regarding stakeholder engagement, specifically including a focus on engagement of un/underserved individuals and their families and the family-led organizations that support them and who have insights from tens of thousands of families from diverse backgrounds reflecting a variety of diverse experiences.

Finally, National PLACE supports the activity to assess treatment utilization to identify disparities in and barriers to access to effective, appropriate, and quality treatment for underserved populations, and implement policies to address identified disparities, but strongly recommends the addition of explicit language regarding stakeholder engagement, specifically including a focus on engagement of un/underserved individuals and their families and the family-led organizations that support them and who have insights from tens of thousands of families from diverse backgrounds reflecting a variety of diverse experiences.

*[Strategic Objective 1.3](#): Expand equitable access to comprehensive, community-based, innovative, and culturally-competent healthcare services while addressing social determinants of health.*

National PLACE endorses this Strategic Objective and its focus on *equitable* access, and access to *comprehensive, community-based, innovative, and culturally competent* healthcare services and addressing *social determinants of health*.

In particular, National PLACE strongly supports the activity to engage community members to provide input to plan and implement services and programs and conduct participatory research to ensure that activities are tailored and responsive to community needs. We recommend specific inclusion of language regarding engagement of individuals with lived experience/intended beneficiaries and their families and not just “community members.”

National PLACE also endorses the activity calling for HHS to ensure the provision of safe, culturally-competent care and services for women, with dedicated focus on African American/Black and American Indian/Alaska Native women and people with lower incomes, during maternal, perinatal, prenatal, and postpartum periods of life, including raised awareness of pregnancy-related risk factors and available benefits. Again, we recommend specific inclusion of language regarding engagement of individuals with lived experience/intended beneficiaries and their families.

National PLACE strongly supports the activity to partner with healthcare organizations, healthcare providers, social service organizations, and other organizations to identify, develop and implement evidence-based community-based healthcare service delivery models to support whole person integrated and coordinated care to improve physical health and behavioral health outcomes. However, we recommend explicit reference to family-led, family-serving organizations whose leadership and staff include individuals with lived experience and their families and not just inclusion of these organizations in the category of “social service organizations” or “other organizations.”

Finally, National PLACE strongly endorses the call for HHS to support community-based participatory research, and other research approaches, to examine the effectiveness of community-based service delivery models, in improving health outcomes across populations, including collecting and stratifying data based on race, ethnicity, national origin (including primary language), sex, sexual orientation, gender identity, and pregnancy, age, disability status, and other population variables. We call for expansion of Patient Centered Outcomes Research Institute funding as one means to achieve this.

*[Strategic Objective 1.4](#): Drive the integration of behavioral health into the healthcare system to strengthen and expand access to mental health and substance use disorder treatment and recovery services for individuals and families.*

National PLACE endorses this Strategic Objective's call to strengthen and expand access to mental health and substance use disorder treatment and recovery services for individuals and families, but strongly recommends the addition of stakeholder engagement, particularly for the most un/underserved individuals and families with lived experience in relevant systems, and the family-led organizations whose leadership and staff are primarily composed of such individuals and their families in each of the identified activities (promotion of research to build the evidence base and best practices, including implementation science research to support the scale up of effective models to identify and treat behavioral and physical health issues of individuals in all healthcare settings, including primary care; and strengthening of health equity research to highlight the diversity of populations, communities and researchers and to ensure that evidence-based treatments are available across race, ethnicity, national origin (including primary language), sex, sexual orientation, gender identity, pregnancy, geographic location, and other demographics.

National PLACE also endorses the activities to support a health workforce including community health workers and peer support specialists knowledgeable in behavioral and physical health interdisciplinary care, and to enhance the capacity of physical health providers to assess, screen, and treat behavioral health conditions by increasing access to treatments for substance use disorders and other disorders and assisting behavioral health providers to coordinate with individuals, families, and communities. We recommend addition of language specifically calling for enhancing the capacity of community health workers, peer support specialists, and health providers to collaborate more effectively and respectfully with diverse individuals and their families as well as the family-led organizations who support them and who have knowledge of the experiences, both positive and negative, of many families from diverse and un/underserved backgrounds.

*[Strategic Objective 1.5](#): Bolster the health workforce to ensure delivery of quality services and care.*

National PLACE supports this Strategic Objective. In particular, we endorse its call to fully implement the HHS Health Workforce Strategic Plan to expand supply, ensure equitable distribution, improve quality, and enhance the use of data and evidence to improve program outcomes while strengthening and diversifying the health workforce. Again, we recommend the addition of explicit language regarding peer supporters, including family peer support, across the health workforce.

National PLACE strongly endorses the call to strengthen the integration of culturally- and linguistically-competent and effective care into the services delivered by the health workforce, and is pleased to see the emphasis on partnering with states, Federal Qualified Health Centers, clinics, schools, other community based organizations and the private sector to ensure the health workforce is appropriately and adequately trained with culturally-competent, evidence-based strategies and education modules for

addressing systemic bias and racism, ableism, and transphobia to reduce health disparities in the communities they serve; coordinating with grant recipients and other funded partners to support training, technical assistance, and use of the National Standards for Culturally and Linguistically Appropriate Services (CLAS) in Health and Health Care and Cultural Humility as foundations for effective and equitable provision of healthcare; and promotion of equity and inclusion, including as it relates to race, ethnicity, and gender, in global commitments, resolutions, and strategies affecting the global health workforce. We call for explicit inclusion of family-led, family-serving organizations as a category of partners instead of lumping these critical organizations into the category of “community-based organizations.”

***Strategic Goal 2: Safeguard and Improve National and Global Health Conditions and Outcomes***

***Strategic Objective 2.1:*** *Improve capabilities to predict, prevent, prepare for, respond to, and recover from emergencies, disasters, and threats across the nation and globe.*

National PLACE strongly supports the call to foster collaboration between key partners and stakeholders at the federal, state, tribal, local, and territorial levels, including partner organizations like the Federal Emergency Management Agency, private sector organizations, and global partners like the World Health Organization to increase awareness of opportunities to develop integrated guidance and plans as well as fill gaps in service and critical functions necessary to better anticipate, identify, and promptly respond to threats, emergencies, and disasters. We also endorse the activity to address health disparities and promote trust, and community resilience, especially for underserved communities disproportionately affected by emergencies, by improving engagement and collaboration across federal, state, tribal, local, and territorial stakeholders and community organizations, and with relevant international partners, ensuring response efforts are informed by health and human services equity principles. Finally, we strongly support the call to provide training, education, and technical assistance to foster a multidisciplinary cadre of culturally-competent public health and research professionals to conduct studies to better understand the human health impacts, including mental health, of public health emergencies and disasters, especially among especially among groups that are disproportionately affected. However, we urge HHS to add language about including stakeholders, including representatives of individuals and families who face the least access and the poorest outcomes and the family-led organizations whose leadership and staff with lived experience and who have experience with a wide variety of diverse individuals and families.

***Strategic Objective 2.2:*** *Protect individuals, families, and communities from infectious disease and non-communicable disease through development and equitable delivery of effective, innovative, readily available, diagnostics, treatments, therapeutics, medical devices, and vaccines.*

National PLACE supports this Strategic Objective, particularly the language in several activities regarding engaging with stakeholders, but recommends addition of explicit language regarding partnering with individuals with lived experience/intended beneficiaries and their families and the family-led organizations whose leadership and staff reflect that lived experience and who have knowledge of what is happening on the ground with diverse populations. In particular, it is critical to explicitly address the need to engage with stakeholders in understanding and effectively addressing vaccine hesitancy.

***Strategic Objective 2.3:*** *Enhance promotion of healthy behaviors to reduce occurrence and disparities in preventable injury, illness, and death.*

National PLACE supports this Strategic Objective but recommends addition of explicit language in each activity regarding engagement with diverse stakeholders to understand the most effective messages to enhance promotion of healthy behaviors.

***Strategic Objective 2.4:*** *Mitigate the impacts of environmental factors, including climate change, on health outcomes.*

National PLACE strongly endorses the call to support multidisciplinary teams, prioritizing engagement of community stakeholders in affected communities at all stages of environmental and climate change health research and program implementation, to develop intervention strategies and gain understanding of the factors that make those strategies successful and replicable. However, we strongly urge explicit inclusion of language regarding not just engagement with “community stakeholders” but also engagement with individuals with lived experience and their families as well as the family-led organizations whose leadership and staff includes such individuals and family members.

### ***Strategic Goal 3: Strengthen Social Well-being, Equity, and Economic Resilience***

***Strategic Objective 3.1:*** *Provide effective and innovative pathways leading to equitable economic success for all individuals and families.*

National PLACE strongly supports this Strategic Objective and its identified strategies. National PLACE agrees with the strategy to facilitate system enhancements and partnerships across the federal government to coordinate resources and technical assistance to individuals and families hoping to achieve sustain[ed] economic independence. Particular strategies/activities endorsed by National PLACE include building the capacity of states, tribes, and territories to expand safety net program coverage, enforce Section 504 of the Rehabilitation Act, streamline eligibility determination, and improve enrollment in order to provide effective assistance to address the economic conditions of underserved populations; encouraging states to collaborate across programs and systems so that families hoping to achieve economic security have access to income and housing support, education, and training as well as work supports, such as childcare, transportation, and Medicaid and health insurance (and note the particular effectiveness of family-led organizations in understanding and working across systems); applying knowledge and best practices to help grantees and partners provide services that focus on social determinants of health and factors that affect economic mobility; reducing barriers to the legal immigration system for refugees and immigrants; enabling research use of data collected through federal funded programs to accelerate the production of evidence on factors affecting refugees’ resettlement outcomes, including those of refugee youth; investing in low-income, tribal, and communities of color through funding opportunities to promote social and economic self-sufficiency to lessen economic inequalities; expanding access to culturally- and linguistically-appropriate employability, economic development, education, and support services for vulnerable refugee populations, through specialized programming and collaboration with federal partners; and expanding the development of resources for communities disproportionately affected by economic inequalities including native and indigenous populations, refugees, and asylees, and facilitation of the translation of materials for the public in multiple languages. We recommend explicit addition of language calling for diverse stakeholder engagement in all aspects of the work, particularly those who represent the most un/underserved individuals with lived experience and their families and the family-led organizations whose leadership and staff reflect this lived experience and who support tens of thousands of individuals and families from diverse backgrounds.

***Strategic Objective 3.2: Strengthen early childhood development and expand opportunities to help children and youth thrive equitably within their families and communities.***

National PLACE supports this strategic objective, but recommends not just a focus on two-generation approaches but also three-generation approaches, which reflects the reality of many diverse cultural communities, such as tribal communities, immigrant communities, and many communities of color. Further, we encourage HHS to include language regarding not just offering trauma-responsive services but also reducing/limiting the re-traumatization that too often occurs within family-serving systems.

National PLACE endorses all of the strategies in the plan, including fostering the physical, emotional, intellectual, language, and behavioral development of children and youth while supporting their families and caregivers; supporting services and programs to improve the social well-being of unaccompanied homeless youth, children and youth who cannot remain in their homes, and refugee children and youth; implementing interventions and multidisciplinary programs that enhance and support early childhood development and learning; and improving early childhood development programs, systems, and linkages through the application of data, evidence, and lessons learned.

Particular activities that National PLACE strongly supports are those related to empowering children, youth, and families with opportunities to engage and have their voices heard in the planning, implementation, and assessment of programs and systems they rely on for care, learning, and other health and well-being supports; promoting evidence-based community engagement, dissemination, and implementation of healthcare and human services best practices among underserved populations to leverage reach and reduce gaps in services; and leveraging research opportunities and access to data, evaluations, and evidence to better inform the development and execution of policies and programs that affect the health, well-being, and livelihoods of children, youth, adolescents, and their families and communities. In addition to the language currently included in these strategies/activities, National PLACE recommends the addition of language calling for engagement of family-led, family-serving organizations in these efforts. National PLACE also calls for the funding family-led, family-serving organizations to engage in this work and support the active, informed engagement of diverse individuals with lived experience and their families, including ensuring the existence of a Statewide Family Network in every state/territory/jurisdiction.

National PLACE also strongly endorses those strategies/activities focused on enhancing access for un/underserved individuals and families, reducing/eliminating disparities, and improving outcomes for those who face the greatest disparities in access and the poorest outcomes. These include the activity to collaborate and coordinate with state, tribal, local, territorial, and other partners to increase awareness of adverse childhood experiences, build capacity to implement prevention and response policies, programs, and practices based on the best available evidence, provide targeted, culturally appropriate trainings and technical assistance, and use data to inform program planning, implementation, and evaluation of adverse childhood experiences prevention and response strategies. Another key activity that National PLACE deeply appreciates is to align eligibility and program requirements across family-serving health and human service systems, and provide family navigation supports, to reduce burden and gaps in services. The most effective and efficient entities to provide family navigation supports are family-led organizations staffed by individuals and family members with lived experience. National PLACE also appreciates and supports the activities calling for enhanced capacity for early childhood programs to include young children with disabilities and developmental delays, and improved access to stable and affordable high quality early care and education of underserved communities and populations including tribal communities and low-income communities and populations.

**Strategic Objective 3.3:** *Expand access to high-quality services and resources for older adults and people with disabilities, and their caregivers to support increased independence and quality of life.*

National PLACE supports this strategic objective and its key strategies; our specific recommendations within each strategy are addressed below.

In terms of enhancing system capacity to address the health, health related outcomes, and social determinants of health for older adults and individuals with disabilities by developing processes, policies, and supports that are person centered and provide quality care for older adults and individuals with disabilities, at home or in community-based settings, National PLACE strongly endorses the activities that call for deployment of approaches to care, including primary care, that promote health and equitable, goal-directed care and self-determination for older adults, persons with disabilities, and caregivers; enhance states' ability to implement Medicaid Home and Community Based Services (HCBS) and incorporate standardized quality measures to assess and track the adequacy of the HCBS community integration on access, availability, quality, experience of care, health outcomes, and the workforce; support healthcare partners, state, community, profit, and non-profit organizations to expand infrastructure related to needs of older adults, persons with disabilities, and caregivers and improve coordination and communication of resources and services such as in-home services, transportation, digital equipment, broadband access and healthcare to meet the day to day and long-term needs of older adults, persons with disabilities, and caregiver; and create pathways for older adults and persons with disabilities from vulnerable immigrant communities, such as refugees and asylees, to access relevant benefits and services, by strengthening the capacity of states, agencies, and providers to deliver services and supply resources that address the needs of these immigrant populations.

National PLACE recommends the inclusion of language explicitly mentioning not just community-based organizations and providers but also family-led organizations.

In terms of ensuring availability and equitable access and delivery of evidence-based interventions that focus on research, prevention, treatment, and care of older adults and individuals with disabilities, National PLACE supports the establishment of supportive policies, strengthened communication and partnership initiatives for intervention dissemination and clinical treatment and care gaps, and strategic alliances for improved disease management; coordination across federal agencies and collaboration with state, local, Tribal, private, and non-profit partners to ensure sufficient availability and equitable distribution and equity in access to evidence-based interventions that prevent onset of symptoms and/or improve management to people diagnosed with multiple chronic conditions. National PLACE also endorses the promotion of self-management programs and behaviors and expansion of referral and delivery systems to promote healthcare quality.

Again, National PLACE recommends the inclusion of language explicitly mentioning not just generic non-profit partners but specifically family-led organizations.

In terms of support for the development and implementation activities to better understand and address the needs of all caregivers across the age and disability spectrum, National PLACE agrees with the activities to develop and disseminate a National Family Caregiving Strategy as required by the Recognize, Assist, Include, Support and Engage (RAISE) Family Caregivers Act of 2017; and leveraging of technical assistance and resources to address the needs of older adult, kinship families, non-kinship, minor caregivers, at the federal, state, territorial, tribal and community levels.

National PLACE recommends additional focus on engagement of individuals with lived experience/ intended beneficiaries and their families from diverse backgrounds, especially those who have been and continue to be un/underserved and who have the worst outcomes.

***Strategic Objective 3.4:*** Increase safeguards to empower families and communities to prevent and respond to neglect, abuse, and violence, while supporting those who have experienced trauma or violence.

National PLACE supports this Strategic Objective. In particular, we strongly support the activity to educate and empower families and communities, including tribes and territories, to recognize and respond to signs of violence and trauma and understand the importance of and need for a comprehensive public health approach.

However, National PLACE strongly recommends that the Strategic Plan recognize that most children, even if they have been abused or neglect in their families, do better if their families are provided with support than if they are removed. Since the vast majority of families are identified as having neglected their children as opposed to abusing them, and since far too often challenges that arise due to poverty are identified as neglect, the plan should include language requiring the provision of supports prior to removal except in the most dangerous situations. In addition, systems should not provide more support (priority for child care vouchers and placements, or increased financial support, for example) for foster parents once children are removed from their family than they provide for families who, if they had access to these preferential services and supports, would not be identified as neglecting their children.

Further, we strongly recommend that the Plan include recognition of the reality that there is racism and discrimination based on poverty that leads to more children being identified as having been abused or neglected, and being removed from their families, if they are of color or low-income under the same circumstances that does not lead to identification as being abused or neglected and does not lead to removal from their families, for white and middle or upper-class families. This recognition of explicit and implicit bias in laws, regulations, child welfare policies and procedures, and practices is critical in order to stop the adverse negative impact on families of color, low-income families, and parents with disabilities. Further, we urge HHS to incorporate strong language about prioritizing the provision of needed supports and services instead of removal, and proactive training, supervision, and monitoring for child welfare workers to limit the negative impact of explicit and/or implicit bias.

To the maximum extent possible under existing law, National PLACE recommends that HHS take action to limit removal of children from their family, including by regulations that exempt parents from the “removal timeline” when they are actively engaged in services or the modification of parental rights is based principally on parental incarceration or detention of the parent by the Department of Homeland Security; requiring states/territories/jurisdictions to report on disproportionality and disparities in access to services in their child welfare system, and to demonstrate that they provided the family services, support, and the time needed to address the reasons for the child’s placement in foster care, and link modification of parental rights to the child’s best interests.

Finally, we strongly recommend inclusion of language in this Strategic Objective focused on children with disabilities, which, in addition to children of color and low-income children, is another over-represented population in the child welfare system, and also prohibit states/territories/jurisdictions from removing children due to their parents’ disability without providing intensive supports, based on the best evidence of effective practices.

#### ***Strategic Goal 4: Restore Trust and Accelerate Advancements in Science and Research for All***

***Strategic Objective 4.1: Improve the design, delivery, and outcomes of HHS programs by prioritizing science, evidence, and inclusion.***

National PLACE strongly supports the strategy to leverage stakeholder engagement, communication, and collaboration to build and implement evidence-based interventions for stronger health, public health, and human services outcomes. In particular, National PLACE endorses the related activities to promote sharing of lessons learned between grantees, from grantees to HHS staff, and where applicable, to the broader community; build participation into research agendas by engaging stakeholders, including those with lived experience and citizen scientists, in the design and revision of evaluation and data collection systems and advancing equity amongst researchers and those communities targeted or underrepresented by research efforts; and improve communication and access to community members to facilitate transparent flow of information and education regarding HHS programs.

***Strategic Objective 4.2: Invest in the research enterprise and the scientific workforce to maintain leadership in the development of innovations that broaden our understanding of disease, healthcare, public health, and human services resulting in more effective interventions, treatments, and programs.***

National PLACE endorses the three key strategies identified under this Strategic Objective: to uphold scientific integrity to promote public trust in the quality of the research enterprise; recruit, retain, and develop a diverse and inclusive scientific workforce to conduct basic and applied research in disease, healthcare, public health, and human services; and support, conduct and translate research into interventions that improve the health and well-being for all. Specifically, National PLACE strongly supports identified activities including promoting transparency and awareness by informing the public on efforts across the Department to ensure the scientific integrity in all research and evidence-building activities; expansion and deployment of evidence-based training, mentorship interventions, fellowships, and other workforce development initiatives that support scientists, especially underrepresented scientists, through critical points of transition in their career trajectories; increasing research and practice opportunities for a diverse range of investigators to address social determinants of health and advance health equity in populations with health disparities; and attracting, developing, and retaining the scientific workforce by establishing a talent management strategic plan with input from government, industry, and academic stakeholders. Most importantly, National PLACE strongly endorses the activities to support and promote the development of partnerships between academic research organizations and health department, healthcare providers, community-based health organizations, and community organizations for relevant rapid implementation research and community-based participatory research to engage communities impacted by the research in the development and dissemination of the research; funding opportunities for research implementing and evaluating community-based and culturally-competent models of healthcare and human services delivery to improve the quality of care received by racial and ethnic minority and sexual minority populations; establishing innovative funding opportunities to identify sources for community partners working on areas of concern who can also provide the health and human services communities with best practices in achieving positive results in interventions, treatments, and programs; and supporting research and innovation to strengthen implementation of evidence-based recommendations for preventive health services in public health and healthcare settings among people that have been underserved. We recommend specific inclusion of language regarding increasing the representation of members of underserved communities in funded research, and increasing PCORI funding opportunities.

*Strategic Objective 4.3: Strengthen surveillance, epidemiology, and laboratory capacity to understand and equitably address diseases and conditions.*

National PLACE endorses the strategies under this Strategic Objective, including expanding capacity to improve laboratory safety and quality, detect and prevent public health threats, monitor health conditions, understand the unique needs of various sub-groups of persons, and establish the pipeline for future professionals; modernize surveillance systems for timeliness, accuracy, and analytic reporting; and engage and learn from partners and stakeholders to inform improvements and innovation.

Activities within this Strategic Objective strongly supported by National PLACE include to leverage existing surveillance efforts to better understand the unique and common needs of various sub-groups of persons by race, ethnicity, national origin (including primary language), sex, sexual orientation, gender identity, pregnancy, education status, income, and other population characteristics (we recommend that disability and special healthcare needs be explicitly identified); building expertise in cutting edge laboratory, surveillance, and epidemiology techniques to address public health threats and disease conditions, including harmful chemical exposures and diseases, antimicrobial resistance pathogens and other emerging pathogens, healthcare-associated infections, chronic diseases that disproportionately affect specific populations (e.g. sickle cell disease), individuals with disabilities, maternal health, and behavioral health; promotion of completeness and accuracy of race and ethnicity variables and other population characteristics—including age, disability status, geographic area, socioeconomic status, national origin (including primary language), and sex, sexual orientation, gender identity, and pregnancy—in laboratory data and data submitted for surveillance purposes in order to better explain the burden of disease and health conditions in diverse populations; partnering across HHS agencies (and we would recommend other federal agencies including Education and Labor) to utilize nationally collected data to create customized surveillance reports to address the incidence of infectious disease in underserved populations; providing actionable information for public health officials, policy makers, and regulators to establish and evaluate exposure and disease interventions within disproportionately affected communities or populations; and identifying and addressing barriers to participation of underserved populations in epidemiologic studies and enhance use of community-based participatory research to ensure studies are meaningful and beneficial to participants.

National PLACE recommends stronger and more explicit language throughout this Strategic Objective and the identified strategies regarding meaningful engagement of un/underserved individuals and families with the funded support of family-led organizations that have greater capacity to translate research into meaningful language for a broad range of constituents and have significant experience with many un/underserved individuals and families that can inform the work of researchers.

*Strategic Objective 4.4: Improve data collection, use, and evaluation, to increase evidence-based knowledge that leads to better health outcomes, reduced health disparities, and improved social well-being, equity, and economic resilience.*

National PLACE strongly supports the strategies identified under this objective, including establishing a Department-wide approach to improve data collection, close data gaps, transform data, and share data for better HHS analysis and evaluation; fostering collaborations to broadly expand data access and sharing to create more opportunities to use HHS data to increase knowledge of health, public health, and human service outcomes; improving data collection and conduct evaluations to understand the drivers for inequities in health outcomes, social well-being, and economic resilience; and strengthening capacity and the use of evaluations at HHS to inform evidence-based decision making

In particular, National PLACE strongly supports the following activities within this strategy:

- Fully implement Section 4302 of the Affordable Care Act to ensure that all HHS national data collection efforts and surveys collect information germane to social determinants of health, including data on race, ethnicity, primary language, disability status, sex, sexual orientation, gender identity, and pregnancy;
- Identify and address data gaps, including surveillance systems, surveys, and other data collection methodologies, that limit the ability to fully examine and assess social determinants of health, outcomes, and conditions of populations served by the Department's health, public health or human services programs or services;
- Facilitate data sharing and access to HHS publicly available data by developing public facing platforms and repositories, and to maximize their value ensure they are easy to find, user-friendly, and in machine- readable format;
- Partner with academic research institutes to catalogue and provide access to the Department's data inventory that matches what researchers need to investigate health inequity across communities and the policy impacts on those inequities;
- Better engage and include community stakeholders and those with lived experience into the policymaking, program improvement, and research processes;
- Integrate social determinants of health data into surveillance systems, electronic health records, clinical decision supports, and other data collection points to improve knowledge and ensure equitable access to quality care and service delivery;
- Ensure HHS-funded projects and research studies assess disparities in outcomes in the use of health or human services, including social determinants of health and while protecting personally identifiable information;
- Support expanded research in various settings and among federal agencies to establish the evidence base for community and system level social determinants of health interventions to achieve health equity for historically underserved communities; and
- Evaluate healthcare utilization, screening, treatment, and survivorship to identify disparities in health outcomes of individuals belonging to multiple underserved groups to inform program improvement and policy development.

***Strategic Goal 5: Advance Strategic Management to Build Trust, Transparency, and Accountability***

National PLACE endorses the four Strategic Objectives in this area, to promote effective enterprise governance to ensure programmatic goals are met equitably and transparently across all management practices; sustain strong financial stewardship of HHS resources to foster prudent use of resources, accountability, and public trust; uphold effective and innovative human capital resource management resulting in an engaged, diverse workforce with the skills and competencies to accomplish the HHS mission; and ensure the security of HHS facilities, technology, data, and information, while advancing environment-friendly practices.

***Strategic Objective 5.1: Promote effective enterprise governance to ensure programmatic goals are met equitably and transparently across all management practices.***

Under the strategy of strengthening governance, enterprise risk management and strategic decision making across HHS to better pursue opportunities and address risks, National PLACE most strongly supports the activity to strengthen the strategic management and planning capacity of the Department and its Divisions to accelerate programmatic impact to improve health, public health, and human services outcomes, but would add language regarding engagement of diverse stakeholders.

Under the strategy of creating a culture of change at HHS to support continuous improvement in program and mission delivery, National PLACE strongly endorses the call to foster the development and success of “communities of practice” and bodies of knowledge throughout the Department to share information, best practices, and create opportunities to cross organizational boundaries to create innovative, responsive solutions; and facilitate collaboration and coordination to increase the use of change management, strategic management, and human-centered design tools and techniques to improve customer experience and program and project management across HHS. Again, we would recommend explicitly including language regarding doing these activities in collaboration with diverse individuals with lived experience/intended beneficiaries and their families with the assistance of family-led organizations led and staffed by people with lived experience and the knowledge of how program and mission delivery is perceived among intended beneficiaries and how programs, supports and services are actually delivered on the ground.

***Strategic Objective 5.2: Sustain strong financial stewardship of HHS resources to foster prudent use of resources, accountability, and public trust.***

National PLACE endorses the strategies under this Strategic Objective to continue to strengthen the financial management environment to prevent and mitigate deficiencies; uphold accountability, transparency, and financial stewardship of HHS resources to ensure program integrity, effective internal controls, and payment accuracy; and build an enhanced financial management workforce able to keep pace with changing contexts. In terms of the specific activities intended to achieve the strategies, National PLACE most strongly supports the following:

- Facilitate continued collaboration across public and private sectors to adopt and advance nationally supported standards, implementation specifications, and certification criteria (but add language regarding collaboration with stakeholders/individuals with lived experience/intended beneficiaries);
- Implement governance structures to provide accurate and timely financial information that demonstrates HHS accountability to stakeholders and facilitates data-driven operational, budget, and policy decisions that enhance equity for all; and
- Strengthen communities of practice for the federal financial management workforce to improve capability, recruitment, retention, and succession planning across the enterprise.

***Strategic Objective 5.3: Uphold effective and innovative human capital resource management resulting in an engaged, diverse workforce with the skills and competencies to accomplish the HHS mission.***

National PLACE supports the strategies under this Strategic Objective, including to build and sustain a strong workforce through improved recruitment, hiring, and retention efforts, leverage training and professional development opportunities to develop and manage a high-performing workforce, and provide leaders and managers with the insight and tools to effectively carry out change management, organizational learning, and succession planning. Particular priorities for National PLACE include:

- Develop and implement the HHS Diversity, Equity, Inclusion and Accessibility (DEIA) Strategic Plan to advance diversity, equity, inclusion, and accessibility in the HHS workforce and remove any potential barriers to diversity, equity, inclusion, and accessibility in the workforce, including establishing a framework to address workplace harassment;
- Leverage incentives and flexibilities to enhance the Department’s competitiveness in the job market, and develop mechanisms to the recruitment, hiring, and retention of a high-caliber and qualified workforce (add diverse workforce representative of the constituents/individuals served);

- Increase diverse demographic representation and promotion outcomes by partnering with hiring managers and leveraging data to make informed decisions regarding recruitment, promotion, and retention strategies consistent with Merit System Principles;
- Facilitate regular engagement between hiring managers, human resources professionals, leaders, and other stakeholders, and support collaborations with public, private, and academic sectors to advance opportunities to recruit, support, and train an ethnically, socially, and experientially diverse workforce.
- Invest in diversity and inclusion efforts, including Employee Resource Groups and interest groups, to increase involvement and participation of the workforce in cultivating a culture of inclusion and equity across the Department;
- Increase leaders' and managers' accountability for delivering results in improving diversity and equity outcomes in their hiring practices and promoting a culture that supports employees in identifying, accessing, and receiving professional development opportunities that are unique to their career needs and aspirations;
- Increase access to diversity and inclusion training and developmental opportunities for HHS leaders, managers, and staff to foster a culture of inclusion and equity among an increasingly diverse workforce;
- Facilitate engagement, collaboration, and communication between HHS leaders, managers, and employees in ensuring a work environment that promotes inclusive policies and flexibilities, such as work schedule flexibilities and remote work opportunities, that are responsive to the Department's evolving needs;
- Promote succession planning for mission-critical occupations to increase organizational resilience and effectiveness by facilitating the regular transfer of institutional knowledge among the workforce (add with special efforts taken to increase succession by individuals from backgrounds that face explicit and implicit bias and discrimination and who are currently under-represented);
- Take a data-driven approach to advancing policies that promote diversity, equity, inclusion, and accessibility within the HHS workforce, while protecting the privacy of employees and safeguarding all personally identifiable information and protected health information; and
- Support, coordinate, and encourage HHS efforts to conduct research, evaluation, and other evidence-building activities to identify leading practices, and other promising practices, for broadening participation and opportunities for advancement in HHS employment, and to assess and promote the benefits of diversity, equity, inclusion, and accessibility for Federal performance and operations and barriers to achieving these goals.

***Strategic Objective 5.4:*** *Ensure the security of HHS facilities, technology, data, and information, while advancing environment-friendly practices.*

National PLACE supports this Strategic Objective and has no specific comments or recommendations.

## **Conclusion**

In conclusion, overall, National PLACE supports the draft HHS Strategic Plan, its Strategic Objectives, strategies, and activities. We recommend expansion and enhancement of language regarding engagement at all levels, with needed supports, of diverse individuals with lived experience/intended beneficiaries of programs, services and supports, their families, and family-led organizations led and staffed by such individuals and family members, particularly individuals and families who face the greatest explicit and implicit bias and discrimination, the least access to quality supports and services, and the poorest outcomes.

The strategic plan must explicitly focus on recognizing and strengthening the role of families as decision-makers for their children and as partners with professionals, providers, and policymakers and providing the needed resources to family-led organizations to enable us to reach, inform, engage, and support families from the full range of diverse backgrounds, including based on race, ethnicity, language, disability or special healthcare needs, immigrant status, gender, sexual orientation, gender identity, geography, involvement in the child welfare or juvenile justice systems, etc.

We further recommend that every strategy that mentions states also explicitly include territories, tribal nations, and DC, and include strategies and activities aimed at addressing the disparate treatment of non-state jurisdictions under many existing federal laws.

National PLACE stands ready to work with HHS in improving and implementing its Strategic Plan for the benefit of our nation's children, youth, adults, and families, especially those least well-served by current systems, programs, services and supports.

Please contact National PLACE's Executive Director, Diana Autin, at [dautin@parentsatthetable.org](mailto:dautin@parentsatthetable.org) to discuss our comments and recommendations in greater detail and to explore the opportunity for collaboration with our 70 national, state, and local members and the networks of Parent Centers, Family to Family Health Information Centers and Family Voices Affiliate Organizations, Statewide Family Networks, National Federation of Families State Organizations and Local Chapters, and Parent to Parent USA members, among others.