



American Association on Health & Disability

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AAHD - Dedicated to better health for people with disabilities through health promotion and wellness



LAKESHORE

November 5, 2021

RE: Public Consultation on the Draft HHS Strategic Plan FY 2022-2026

Submitted electronically to: HHSPPlan@HHS.gov

U.S. Department of Health and Human Services
Office of the Assistant Secretary for Planning and Evaluation, Strategic Planning Team
Attn: Strategic Plan Comments
200 Independence Avenue, SW, Room 434E
Washington, DC 20201

Strategic Planning Team:

The American Association on Health and Disability and the Lakeshore Foundation provide comments on the HHS draft strategic plan. Our comments are consistent with those submitted by the Consortium for Citizens with Disabilities (CCD), and we support the CCD statement. We go beyond the CCD statement detailing quality measurement approaches; focusing on the need for effective integration for persons dually eligible for Medicare and Medicaid; endorsing “bi-directional” behavioral health-general health-primary care integration; focusing on the particular and complex challenges faced by a variety of persons with co-occurring disabilities and chronic conditions; and grappling with the search for consistency in disability and related demographic data collection, analysis, and public reporting/transparency.

The American Association on Health and Disability (AAHD) (www.aahd.us) is a national non-profit organization of public health professionals, both practitioners and academics, with a

primary concern for persons with disabilities. The AAHD mission is to advance health promotion and wellness initiatives for persons with disabilities. AAHD is specifically dedicated to integrating public health and disability into the overall public health agenda.

The Lakeshore Foundation (www.lakeshore.org) mission is to enable people with physical disability and chronic health conditions to lead healthy, active, and independent lifestyles through physical activity, sport, recreation and research. Lakeshore is a U.S. Olympic and Paralympic Training Site; the UAB/Lakeshore Research Collaborative is a world-class research program in physical activity, health promotion and disability linking Lakeshore's programs with the University of Alabama, Birmingham's research expertise.

Overview Comments

AAHD is an active member of the Consortium for Citizens with Disabilities (CCD) Health and Long Term Services and Supports Task Forces. The CCD health task force co-chairs have submitted comments in response to the request for public comment on the Draft HHS Strategic Plan for FY 2022-2026. We were engaged in developing some of these comments.

Our comments are consistent with those submitted by the Consortium for Citizens with Disabilities (CCD), and we support the CCD statement. We go beyond the CCD statement detailing quality measurement approaches; focusing on the need for effective integration for persons dually eligible for Medicare and Medicaid; endorsing "bi-directional" behavioral health-general health-primary care integration; focusing on the particular and complex challenges faced by a variety of persons with co-occurring disabilities and chronic conditions; and grappling with the search for consistency in disability and related demographic data collection, analysis, and public reporting/transparency.

We endorse the CCD introductory comments – We appreciate many aspects of this Strategic Plan, particularly the focus on addressing health inequities and disparities. We also appreciate HHS's explicit recognition that people "may belong to more than one underserved community and face intersecting barriers."

Objective 1.1: Increase choice, affordability, and enrollment in high-quality healthcare coverage

Shortly after implementation of the Affordable Care Act (ACA) began, AAHD received a Robert Wood Johnson Foundation grant to establish and operate the National Disability Navigator Resource Collaborative (NDNRC). The Collaborative continues today.

CCD approves of HHS putting choice, affordability, and enrollment as its first objective. For years, people with disabilities have struggled disproportionately with rising health care costs. The Affordable Care Act (ACA) and subsequent legislation have helped level the playing field, by, for example, limiting medical underwriting and insurance rescissions. The ACA also largely eliminated high-risk pools that had greatly increased premiums for people with disabilities, and created critical new pathways to affordable coverage for people with disabilities, such as Medicaid expansion and premium tax credits. Rough estimates suggest that 20 to 30% of

Medicaid expansion adults have disabilities.¹ Before the ACA, many of these individuals would have had no access to affordable health care. Medicaid expansion has led to greater flexibility for people with disabilities in seeking employment as well. Evidence shows that people with disabilities have higher rates of employment in expansion states vs. non-expansion states and that overall employment rates increased in expansion states.^{2 3}

Promote available and affordable healthcare coverage to improve health outcomes in our communities.

Empower consumers with choices for high quality healthcare coverage.

High-quality health care coverage must be comprehensive.

We recommend that HHS commit to discontinuing any policies that apply premiums, high cost sharing, or other added conditions of eligibility in Medicaid and other health programs targeted at low-income populations.

We recommend HHS not approve any waiver proposal (whether § 1115, § 1915, or § 1332) without analysis of its potential effects on marginalized communities and its plan to bolster health equity as part of the innovation. This analysis should include a determination of the proposed waiver's effect on community living for people with disabilities.

We support the proposal to “monitor equitable and timely access to Medicaid and Children's Health Insurance Program (CHIP) providers and services.”

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

Implement and assess approaches to improve healthcare quality, and address disparities in healthcare quality, treatment, and outcomes

We recommend that HHS use the term “services” rather than “treatment” to encompass the full range of programs HHS oversees and non-medical services are particularly important to people with disabilities.

CCD supports the strategy to promote and support implementation of the National Standards for Culturally and Linguistically Appropriate Services (CLAS) in Health and Health Care by health professionals, health systems and organizations and in HHS programs to improve the quality of

¹ David Machledt, National Health Law Program, *Faces of Medicaid Expansion* (May 22, 2017), <https://healthlaw.org/resource/the-faces-of-medicaid-expansion-filling-gaps-in-coverage/>.

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care and reduce health disparities by ensuring the provision of services that are respectful of and responsive to individuals' health needs, preferences, culture, and preferred language.

With respect to quality measures, we recommend HHS adopt the “CMS Meaningful Measures” approach, with the addition of HCBS (home-and-community-based services) and LTSS (long-term services and supports). AAHD has been an active member of several National Quality Forum (NQF) committees since 2012, including currently serving on the NQF Measure Applications Partnership (MAP) Coordinating Committee. CMS has continually refined and expanded its “Meaningful Measures” initiative. CMS Meaningful Measures contain many of the major elements that the health and disability communities have been engaged in. CMS has done far more than any other HHS unit in quality measurement. Included: patient (participant) reported measures (PROs); person-centered “care;” chronic conditions; seamless “care” coordination; equity; wellness and prevention; determinants of health, and behavioral health. Emphasized is the “Consumer and Caregiver Voice.” The disability community prefers use of the terms “services and supports” rather than “care.”

Strengthen rules and enforcement to prohibit discriminatory benefit design in formularies and other benefit designs that explicitly discriminate against people with disabilities.

Objective 1.3: Expand equitable access to comprehensive, community-based, innovative, and culturally-competent healthcare services while addressing social determinants of health

Support community-based services to meet the diverse healthcare needs of underserved populations.

We strongly agree with HHS’s strategy to support community-based services. It is critical that this strategy include supporting the right of people with disabilities to receive long-term services and supports at home and in the community.

We urge HHS to ensure effective communication with people with disabilities, including by providing plain language versions and ensuring that internet communications are made screen reader accessible and adhere to the guidelines created by the Web Accessibility Initiative (WCAG).

We strongly support increasing access to affordable and accessible housing. Housing is a primary social determinant of health, and for people with disabilities lack of accessible and affordable housing is also a barrier to HCBS.

We recommend that enhancing civil rights regulations and enforcement be a key strategy to advancing health equity and reducing disparities. We urge the administration to continue to address discriminatory policies and practices by hospitals, and health care systems, and state policies.

We appreciate inclusion of disability status in data collection, but note that current approaches to defining and asking about disability status varies greatly to the point where comparisons across

data sets are often impossible. The CCD submission advocates use of the Americans with Disability Act and American Community Survey definitions. CCD further requests that HHS collect and report data on residential (congregate) setting.

AAHD and Lakeshore previously recommended: Collect, Analyze, and Publicly Report - Appropriate agencies of the federal government in all COVID-19 testing, cases, and deaths, in all settings and by setting, should collect, analyze, and regularly publicly report COVID-19 and co-occurring demographic factors including **disability status**, race, ethnicity, sex, age, primary language, sexual orientation, gender identity, and socio-economic status. Ideally, the data system analysis should be able to cross-walk between these various precise demographic factors; for example, disability status and race. This COVID-19 disability status data template should serve for use in all public health and health funded programs.

There needs to be a consistent use of disability status data.

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

Bi-Directional Primary Care and Behavioral Health Integration

We strongly support the May 2021 National Academy of Medicine report - “Implementing High Quality Primary Care” report and its call for fundamental primary care modernization.

We strongly support the March 2021 Bipartisan Policy Center report – “Tackling America’s Mental Health and Addiction Crisis Through Primary Care Integration.”

Complexity cases (chronic conditions and co-morbid behavioral health conditions) absorb 80% of total national healthcare expenditure. Conditions such as diabetes, cancer, heart disease, arthritis, COPD, etc have a 20-40% possibility of a BH co-morbidity. Medical claims data show cost for physical illness only (\$4,090) *doubles* when mental illness added (\$9,036), and *quadruples* when physical, mental and substance use all present (\$19,018). Kathol et al, *Journal of General Internal Medicine* 20; 160-167, 2005.)

Another example of need to focus on chronic conditions and BH integration are the 12.3 million (2019) individuals enrolled in both Medicare and Medicaid (dual eligible persons). Many dually eligible persons have complex care needs, including chronic illness, physical disabilities, behavioral health issues and cognitive impairments. They on average use more services and have higher per capital costs those beneficiaries enrolled in Medicare or Medicaid alone. Many live with major social risk factors. Although Congress created multiple authorities to integrate their care, currently only about 10% are enrolled in integrated care programs (CMS MMCO financial alignment; PACE; D-SNPS; and Medicaid Managed LTSS programs). The division of coverage between Medicare and Medicaid results in fragmented care and cost shifting. A recent RAND study, commissioned by CMS, documented dually eligible persons in Medicare Advantage programs had much greater clinical care quality disparities (using HEDIS measures) than non-dually eligible persons. 2021 studies on the dually eligible population have been

published by MEDPAC, Health Management Associates, Alliance for Health Policy, and RAND for CMS.

Congress and the Administration should accelerate the expansion of existing models and design and pilot further programs to more effectively integrate all aspects of services and supports for persons dually eligible for Medicare and Medicaid.

AAHD and Lakeshore join many behavioral health organizations advocating “bi-directional” integration. General health and primary care should effectively integrate behavioral health and behavioral health plans, systems, and providers should effectively integrate general health/physical health.

People present to a health care provider with the full array of presenting problems – diabetes, heart problems, high blood pressure, substance use, mental health challenges, etc. The movement in the system is to treat the “whole person’s health,” not just a piece of their challenge and ignoring counter-indicated medications and other considerations. The effort is to have the entire health system treat the person’s whole health needs. Health plans and group practices are increasingly focused on bi-directional, integrated, whole health and wellness. Whole person health and wellness requires that general health-primary care meaningfully integrate behavioral health and behavioral health providers meaningfully integrate general health-primary care.

Persons with Co-Occurring Disability and Behavioral Health Conditions: State Behavioral Health Systems, State Intellectual Disability-Developmental Disability Systems-and State Aging and Disability Systems

While the exact prevalence of the co-occurrence of ID-DD (intellectual disability and other developmental disabilities) and mental illness is not precise, recent research has emphasized and estimated the prevalence between 30-and-40%. Issues are attributable to rigid state infrastructure and financing parameters. A few states have overcome these issues through collaboration and innovative design strategies.

The 21st Century Cures Act [PL 114-255; section 8008 (b) (5) (A) (ii)] identifies the need for states to provide an organized community-based system of services and supports for persons with co-occurring mental illness and disabilities.

[See NASDDDS-NADD-NASMHPD, Supporting Individuals with Co-Occurring Mental Health Needs and ID-DD, May 2021; and, NASDDDS-HSRI, National Core Indicators Data Brief – What Do NCI Data Reveal About People Who Are Dual Diagnoses with ID-DD and Mental Illness, October 2019.]

Greater efforts must be made to meaningfully integrate federal and state currently siloed federal-state discretionary grant programs (such as the SAMHSA Mental Health Block Grant and the SAMHSA Substance Use Prevention and Treatment Block Grants) to better serve persons with co-occurring ID-DD and behavioral health challenges; and persons with co-occurring disability and chronic health conditions which includes behavioral health challenges.

Each federal grant program to the states (administered by ACL and SAMHSA) should be required to document the number of persons with co-occurring conditions, and the kinds of services and supports they receive.

In strengthening health equity research to ensure evidence-based treatments are available, we recommend HHS include disability status as a demographic category.

Objective 1.5: Bolster the health workforce to ensure delivery of quality services and care

It is paramount to build the workforce with people with disabilities in mind. We support strategies to promote employment for people with disabilities throughout the healthcare workforce.

We also enthusiastically agree with CCD, mental health organizations, and public health organizations on enhancing support for peer support specialists as part of the behavioral health workforce and community-based intervention services, as well as the variety of important roles played by community health workers.

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

Leverage opportunities for improved collaboration and coordination to strengthen capacity for effective emergency and disaster readiness, response, and recovery. Often, people with disabilities are routinely overlooked and underserved before, during, and after disasters.

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

We join CCD and urge HHS to ensure that public health promotion, such as promotion of physical activity, includes efforts to improve the health of people with disabilities.

Specifically, the Lakeshore Foundation (www.lakeshore.org) mission is to enable people with physical disability and chronic health conditions to lead healthy, active, and independent lifestyles through physical activity, sport, recreation and research. Lakeshore is a U.S. Olympic and Paralympic Training Site; the UAB/Lakeshore Research Collaborative is a world-class research program in physical activity, health promotion and disability linking Lakeshore's programs with the University of Alabama, Birmingham's research expertise.

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.

We strongly support HHS naming expanding people with disabilities' access to high-quality services to support increased independence and quality of life as an objective.

Enhance 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.

We believe HHS should prioritize strong implementation of the CMS Medicaid HCBS Settings Rule, including by providing additional guidance, technical assistance (TA) to states, and ongoing monitoring, with a focus on the heightened scrutiny process.

We support enhancing states' ability to implement Medicaid 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. We urge CMS to finalize and work with states to implement core quality measures for HCBS that emphasize person-centered services, compliance with the HCBS Settings Rule, equity in access to HCBS, and best practices.

With respect to quality measures, we recommend HHS adopt the "CMS Meaningful Measures" approach, with the addition of HCBS and LTSS. AAHD has been an active member of several National Quality Forum (NQF) committees since 2021, including currently serving on the NQF Measure Applications Partnership (MAP) Coordinating Committee. CMS has continually refined and expanded its "Meaningful Measures" initiative. CMS Meaningful Measures contain many of the major elements that the health and disability communities have been engaged in. CMS has done far more than any other HHS unit in quality measurement. Included: patient (participant) reported measures (PROs); person-centered "care;" chronic conditions; seamless "care" coordination; equity; wellness and prevention; determinants of health, and behavioral health. Emphasized is the "Consumer and Caregiver Voice." The disability community prefers use of the term "services and supports," rather than "care."

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

We support HHS's strategies to improve data collection. We appreciate inclusion of disability status in data collection, but note that current approaches to defining and asking about disability status varies greatly to the point where comparisons across data sets are often impossible. The CCD submission advocates use of the Americans with Disability Act and American Community Survey definitions. CCD further requests that HHS collect and report data on residential (congregate) setting.

We previously recommended: Collect, Analyze, and Publicly Report - Appropriate agencies of the federal government in all COVID-19 testing, cases, and deaths, in all settings and by setting, should collect, analyze, and regularly publicly report COVID-19 and co-occurring demographic factors including **disability status**, race, ethnicity, sex, age, primary language, sexual orientation, gender identity, and socio-economic status. Ideally, the data system analysis should be able to cross-walk between these various precise demographic factors; for example, disability status and

race. This COVID-19 disability status data template should serve for use in all public health and health funded programs.

Thank you for the opportunity to comment. If you have any questions please contact Clarke Ross at clarkeross10@comcast.net.

Sincerely,



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RE: Public Consultation on the Draft HHS Strategic Plan FY 2022-2026

Strategic Planning Team:

The Consortium for Citizens with Disabilities (CCD) Health and Long Term Services and Supports Task Forces write in response to your request for public comment on the Draft HHS Strategic Plan for FY 2022-2026. CCD is the largest coalition of national organizations working together to advocate for federal public policy that ensures the self-determination, independence, empowerment, integration and inclusion of children and adults with disabilities in all aspects of society.

We appreciate many aspects of this Strategic Plan, particularly the focus on addressing health inequities and disparities. We support HHS's adoption of the definition of underserved populations listed in Executive Order 13985: Advancing Racial Equity and Support for Underserved Communities through the Federal Government, which includes people with disabilities and other individuals who belong to underserved communities, such as Black, Latino, and Indigenous and Native American persons, Asian Americans and Pacific Islanders and other persons of color; members of religious minorities; LGBTQ+ persons; persons who live in rural areas; and persons otherwise adversely affected by persistent poverty or inequality. We also appreciate HHS's explicit recognition that people "may belong to more than one underserved community and face intersecting barriers."

Below we offer recommendations for ensuring the needs of people with disabilities are considered and addressed in specific objectives and strategies.

Objective 1.1: Increase choice, affordability, and enrollment in high-quality healthcare coverage

CCD approves of HHS putting choice, affordability, and enrollment as its first objective. For years, people with disabilities have struggled disproportionately with rising health care costs. The Affordable Care Act (ACA) and subsequent legislation have helped

level the playing field, by for example, limiting medical underwriting and insurance rescissions. The ACA also largely eliminated high-risk pools that had greatly increased premiums for people with disabilities, and created critical new pathways to affordable coverage for people with disabilities, such as Medicaid expansion and premium tax credits. Rough estimates suggest that 20 to 30% of Medicaid expansion adults have disabilities.¹ Before the ACA, many of these individuals would have had no access to affordable health care. Medicaid expansion has led to greater flexibility for people with disabilities in seeking employment as well. Evidence shows that people with disabilities have higher rates of employment in expansion states vs. non-expansion states and that overall employment rates increased in expansion states.^{2 3}

Even after these important steps, there is still a long, steep pathway ahead to fully rectify disparities for people with disabilities. Over the past few years, restrictive enrollment and redetermination policies in some state Medicaid agencies led to dwindling enrollment for youth and adolescents. Access to robust Marketplace coverage has also been weakened by reductions in funding for Marketplace navigators and increased authorization of misleading short-term health plans that offer flimsy coverage, and rising deductibles and cost sharing.

Promote available and affordable healthcare coverage to improve health outcomes in our communities

We support the strategy to enhance and support outreach efforts to inform eligible individuals of healthcare insurance options and related cost-saving opportunities. It is particularly important to ensure that people with disabilities are afforded effective support for enrollment through navigator support. People with disabilities often have more health care needs and must consider numerous factors when selecting insurance coverage, such as whether established providers are in network and whether multiple medications are covered with affordable cost-sharing. Therefore, it is critical that HHS continue to support robust access to free enrollment assisters who provide impartial assistance to people with disabilities in selecting a plan and enrolling in cost-sharing assistance, as well as Medicaid and CHIP if they are eligible. We applaud the Administration's expansion of the funding for the navigator program this year and recommend that it continue and that CMS encourage partnerships with local consumer based disability organizations to conduct outreach and enrollment to the disability community as locally trusted entities.

Empower consumers with choices for high quality healthcare coverage

- We agree that reforms should emphasize transparency in relation to pricing, provider availability, cost-sharing, service availability, grievance and appeals, and

¹ David Machledt, National Health Law Program, *Faces of Medicaid Expansion* (May 22, 2017), <https://healthlaw.org/resource/the-faces-of-medicaid-expansion-filling-gaps-in-coverage/>.

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all other elements of health coverage. However, transparency does not obviate the need for lower cost-sharing. As [our principles on health reform](#) make clear, health care coverage must be affordable for all people, including people with disabilities and others who have higher than average health costs. Ensuring that premiums are affordable is necessary, but insufficient to ensure affordable access to care. Deductibles and other cost-sharing must also be affordable. Premiums and out-of-pocket costs should be nominal or non-existent for low-income populations. First dollar coverage helps people with disabilities who need access to care and treatment on a routine basis have predictable and affordable co-pays. Deductibles and out-of-pocket caps should also be limited based on household income, recognizing that people with disabilities often have higher than average out of pocket medical expenses.

- We recommend policies that pursue cost-control mechanisms other than utilization management. Utilization management, such as prior authorization or step therapy, disproportionately impacts people with disabilities and chronic conditions who frequently need high-cost, high-intensity care and do not have lower-cost alternatives. Data shows that many insurers employ utilization controls such as step therapy via protocols that are more restrictive than the standard of care.⁴ Many states eased or eliminated prior authorization during COVID-19, and this did not dramatically increase health care usage. Policymakers should analyze data from this experience and reconsider the frequent application of prior authorization as a barrier to needed services, rather than a tool to improve care quality.
- High-quality health care coverage must be comprehensive. In order to be comprehensive, we believe that any health care coverage must include robust coverage of Home and Community Based Services (HCBS), habilitation and rehabilitation services, behavioral health, prescription drugs, dental, vision, and hearing.
- We recommend that HHS commit to discontinuing any policies that apply premiums, high cost sharing, or other added conditions of eligibility in Medicaid and other health programs targeted at low-income populations. We appreciate that HHS has already rescinded guidance and most approvals related to work requirements from the prior administration. In prior administrations, several states have sought and received approvals for § 1115 projects that impose premiums, heightened cost sharing, work requirements or other waivers of key Medicaid protections that reduce access to care. Such waivers have no meaningful innovative or experimental value. We already know premiums (and high cost sharing) substantially reduce access to coverage and care, particularly for low-income individuals and families. Work requirements cause massive coverage losses – often due to administrative and reporting problems – and do not meaningfully increase employment.⁵ Work requirements in different safety net

⁴ <https://www.healthaffairs.org/doi/abs/10.1377/hlthaff.2021.00822?journalCode=hlthaff>

⁵ Robin Rudowitz & MaryBeth Musumeci, *An Early Look at State Data for Medicaid Work Requirements in Arkansas* (2018), <http://files.kff.org/attachment/Issue-Brief-An-Early-Look-at-State-Data-for-Medicaid-Work-Requirements-in-Arkansas>.

programs also disproportionately disenroll people with disabilities.⁶ Moreover, many of these policies exacerbate health inequities.

- We recommend HHS not approve any waiver proposal (whether § 1115, § 1915, or § 1332) without analysis of its potential effects on marginalized communities and its plan to bolster health equity as part of the innovation. This concrete step would go a long way toward making HHS's Strategic objective on affordability, choice and enrollment more than just words on a page. We appreciate HHS's recent rule that strengthens § 1332 waiver guardrails on affordability, comprehensiveness, and coverage. In the past, these reviews have included a review of each proposals' effects on different subpopulations within the target group. This could serve as a starting point for a new commitment to incorporate a robust equity analysis as a required element for new waiver proposals of any kind. This analysis should include a determination of the proposed waiver's effect on community living for people with disabilities.
- We support the proposal to "monitor equitable and timely access to Medicaid and Children's Health Insurance Program (CHIP) providers and services." People with disabilities rely on Medicaid for access to basic health care services and for services that ensure their functioning, independence, and well-being, including: nursing and personal care services, specialized therapies, intensive mental health services, special education services, and other needed services that are unavailable through other insurance. Access to these services is a matter of life, death, independence, and dignity for the millions of people with disabilities on Medicaid and the protections provided by the equal access statute are of particular importance to our community. CCD has long supported CMS taking regulatory action to enforce the provisions at 1902(a)(30)(A) to ensure that people with disabilities who rely on Medicaid have adequate access to health care and home and community-based services and supports by ensuring that service providers have adequate reimbursement rates. Too often the reimbursement rates do not reflect the actual cost of providing the services and supports. Inadequate reimbursement rates contribute to low wages and high turnover rates for the direct support professionals which is creating a nationwide crisis disrupting the lives of beneficiaries and putting their health and safety at risk. Such enforcement must include managed care and HCBS.

Leverage knowledge and partnerships to increase health coverage enrollment

- We appreciate that HHS will conduct research into the cost-effectiveness and affordability of insurance coverage for diverse populations. We believe such research is necessary to address health disparities. HHS should ensure that such research does not exacerbate discrimination by relying on discriminatory metrics like the Quality Adjusted Life Year (QALY). The QALY is a discriminatory

⁶ Andrew J. Cherlin et. al., *Operating within the Rules: Welfare Recipients' Experiences with Sanctions and Case Closings*, 76 Soc. Serv. Rev. 387, 398 (2002) (finding that individuals in "poor" or "fair" health were more likely to lose TANF benefits than those in "good," "very good," or "excellent health") (attached); Vicki Lens, *Welfare and Work Sanctions: Examining Discretion on the Front Lines*, 82 Soc. Serv. Rev. 199 (2008).

measure based on the idea that disabled lives are less valuable and less worth living than non-disabled lives. CCD opposes the use of QALYs and related measures and supports an explicit ban on the use of QALYs in any health care policy that considers the value or effectiveness of treatments or health care.

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

Partner with providers to develop payment models and other incentives to expand options for quality care at lower costs

- We welcome the opportunity to help “design innovative, targeted, value-based payment models to increase recruitment of providers that care for predominantly underserved populations and provide them with support to improve their awareness of the benefits of alternative payment models that aim to decrease health inequities.” It is important to note that value-based payments should have the primary goal of improving health, not punishing providers or patients for poor health. Many states have adopted (or attempted to adopt) Medicaid waiver programs that are designed to “incentivize” healthy behaviors. We strongly object to these programs. The use of high-cost sharing, utilization management, and other barriers is sometimes discussed as giving patients “skin in the game” to reduce their utilization of care. In reality, these programs only put greater burdens on people with disabilities and chronic conditions and limit their access to needed care. Alternative payment models and other efforts to control costs should seek to expand and improve access to care, not limit it.

Implement and assess approaches to improve healthcare quality, and address disparities in healthcare quality, treatment, and outcomes

- We recommend that HHS use the term “*services*” rather than “*treatment*” to encompass the full range of programs HHS oversees and non-medical services are particularly important to people with disabilities.
- CCD supports the strategy to promote and support implementation of the National Standards for Culturally and Linguistically Appropriate Services (CLAS) in Health and Health Care by health professionals, health systems and organizations and in HHS programs to improve the quality of care and reduce health disparities by ensuring the provision of services that are respectful of and responsive to individuals' health needs, preferences, culture, and preferred language.
- With respect to quality measures, we recommend HHS adopt the “CMS Meaningful Measures” approach, with the addition of HCBS and LTSS.

Strengthen patient safety improvements and access to affordable medications and medical products to reduce spending for consumers and throughout the healthcare system

Prescription drugs are an essential aspect of daily life for many people with disabilities

and chronic conditions. As the administration considers policy proposals to reduce the cost of prescription drugs, we encourage policymakers to keep the needs of people with disabilities and chronic conditions at the forefront of all discussions. As our [Positions on Access to Prescription Drugs](#) state, we believe that all people should have access to treatment that is affordable, accessible, easy to navigate, and based on a physician-directed and person-centered treatment plan determined by the individual and their health care providers. We have several recommendations in order to achieve this goal:

- Strengthen rules and enforcement to prohibit discriminatory benefit design in formularies and other benefit designs that explicitly discriminate against people with disabilities, such as through placing higher prior authorization or cost sharing requirements on treatments for certain conditions or placing all drugs to treat a condition on the specialty tier.
- Do not weaken consumer protections (including Medicaid's broad outpatient prescription drug requirements and Medicare's six protected classes) or allow limitations on access to treatment to extract price concessions from manufacturers. Insurance practices like step therapy, prior authorization, cost-sharing designs, and tiered formulary design are used in negotiation with pharmaceutical manufacturers and other providers and manufacturers to extract discounts, but they directly harm people with disabilities and chronic conditions who have higher needs and higher costs.
- To the extent measures of cost-effectiveness or comparative effectiveness are used in determining drug formularies, utilization management, or cost sharing, prohibit the use of Quality-Adjusted Life Years and other similar metrics which discriminate against people with disabilities.
- Increase options for individuals to lower their out of pocket costs, including access to safe and effective generics, while not unduly restricting coverage of brand name drugs. Many people with disabilities may not be able to take a generic, due to drug interactions, side effects, ineffectiveness, or inability to obtain a list of all ingredients in the generic drug.

Objective 1.3: Expand equitable access to comprehensive, community-based, innovative, and culturally-competent healthcare services while addressing social determinants of health

Support community-based services to meet the diverse healthcare needs of underserved populations

- We strongly agree with HHS's strategy to support community-based services. It is critical that this strategy include supporting the right of people with disabilities to receive long-term services and supports at home and in the community.
- We appreciate HHS's plans to increase access to oral health care and ensure it is integrated with primary care. People with disabilities are more likely than the general population to experience barriers to good oral health, including lack of coverage, conditions and/or treatments that exacerbate oral health needs, and few accessible oral health care providers. For example, 62% of individuals with

disabilities under 65 on Medicare report that they have not seen a dentist in the last year. Therefore, we encourage HHS to take steps across Medicare, Medicaid and other sources of health care coverage to expand access. For example, people with disabilities on Medicare may need dental care before they can get a surgery or treatment. We urge HHS to expand access to such services under its existing “medically necessary” authority. In addition, to expand access for people with disabilities, it is critical that dentist offices are accessible and that providers are equipped and trained to serve them.

- We also support improving access to telehealth services in accordance with our [CCD Health Task Force Telehealth Principles](#).

Remove barriers to healthcare access to advance health equity and reduce disparities

- As previously mentioned, we support strategies to integrate and promote CLAS. We note that cultural competency includes disability competence and accessibility, and that these competencies intersect with other cultural competencies including linguistically appropriate services. For example, documents that are translated into non-English languages also need to be made available in accessible formats in those languages.
- We urge HHS to ensure effective communication with people with disabilities, including by providing plain language versions and ensuring that internet communications are made screen reader accessible and adhere to the guidelines created by the Web Accessibility Initiative (WCAG).
- We strongly support increasing access to affordable and accessible housing. Housing is a primary social determinant of health, and for people with disabilities lack of accessible and affordable housing is also a barrier to HCBS. We urge HHS to collaborate with the U.S. Department of Housing and Urban Development (HUD) regarding targeting affordable, integrated, accessible housing to people transitioning from, or at risk of entering, institutions and carceral settings; and provide technical assistance to states about leveraging Medicaid for housing-related supports.
- We recommend that enhancing civil rights regulations and enforcement be a key strategy to advancing health equity and reducing disparities. In particular, we are encouraged that HHS is planning to engage in rulemaking on Section 1557 of the ACA. We urge quick action to not only restore the health care rights that have been gutted but also improve upon 1557 and other anti-discrimination protections for people with disabilities, including by ensuring that regulations implementing Section 1557 clearly outline key ways in which health insurance benefit design may discriminate based on disability.
- We urge the administration to continue to address discriminatory policies and practices by hospitals, health care systems, and state policies, including regarding Crisis Standards of Care, access to organ transplants, and other instances of disability discrimination. The administration should finalize the rulemaking that HHS’s Office for Civil Rights initiated concerning these issues.
- In developing patient safety bundles and decision aids for health conditions that disproportionately affect underserved populations, people with lived experience

must be consulted.

- We appreciate inclusion of disability status in data collection, but note that current approaches to defining and asking about disability status vary greatly to the point where comparisons across data sets are often impossible. Where possible we encourage HHS to use a more standardized, inclusive definition of disability, based on the ADA definition, and start from the six-question standard used by the American Community Survey. We also ask that HHS collect and report data on residential settings (i.e., whether someone lives in a congregate setting).

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

- We strongly support efforts to better integrate behavioral health and primary care and LTSS delivery. We urge expansions of models and programs to better integrate care for people with disabilities and chronic conditions, including people who are dually eligible for Medicare and Medicaid. We also agree with enhancing support for peer support specialists as part of the behavioral health workforce and community-based intervention services.
- In strengthening health equity research to ensure evidence-based treatments are available, we recommend HHS include disability status as a demographic category. Many people who have mental health disabilities also have other co-occurring disabilities. In research and development of programs and best practices, we urge HHS to work with people with lived experience, including people with co-occurring mental and non-mental health disabilities, and ensure that their perspectives are central in decisions concerning these services.

Objective 1.5: Bolster the health workforce to ensure delivery of quality services and care

- It is paramount to build the workforce with people with disabilities in mind. We support strategies to promote employment for people with disabilities throughout the healthcare workforce.
- HHS must work with states and stakeholders to develop strategies to address workforce shortages and high turnover in Medicaid HCBS programs in particular. Currently, the essential workforce that provides HCBS is severely underpaid due to inadequate Medicaid rates paid to providers. The result is a community service delivery system that a survey of over 3,000 providers in 26 states indicates is challenged by high direct care vacancy rates and an average turnover rate of 43%, with numerous states reporting turnover in excess of 50%.

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

Leverage opportunities for improved collaboration and coordination to strengthen capacity for effective emergency and disaster readiness, response,

and recovery

- Often, people with disabilities are routinely overlooked and underserved before, during, and after disasters. This begins when people with disabilities are left out of emergency preparedness processes, which then disproportionately impacts them during disasters. The consequences have been catastrophic. It is essential that emergency management programs are developed with people with disabilities in mind. People with disabilities have unique needs, even with regard to disaster preparedness. They must have the necessary information and access to resources to enable them to make plans for and respond to emergencies. While recognizing that emergency preparedness begins with individuals, people with disabilities must have access to guidance, tool kits and other materials that are in accessible and understandable formats whether in written form or on line. With respect to health care in particular, maintaining access to prescription drugs and home- and community-based services (HCBS) are critical for people with disabilities. Interruptions in drug regimens or support with activities of daily living can be a matter of life and death.

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

- We urge HHS to ensure that public health promotion, such as promotion of physical activity, includes efforts to improve the health of people with disabilities.
- We call on HHS to end the use of wellness programs in employer-sponsored insurance, end the demonstration promoting wellness programs in Marketplace plans, and reverse the decision to allow issuers to include wellness programs in quality improvement activities. The past two administrations have promoted the use of “wellness programs” in commercial insurance. Health-contingent wellness programs that incur financial penalties or require disclosure of private information to employers discriminate against people with disabilities, and evidence now shows that they also do not improve health or control costs.

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.

- We strongly support HHS naming expanding people with disabilities’ access to high-quality services to support increased independence and quality of life as an objective. As a threshold matter, we recommend HHS work to identify racial and other inequities in HCBS and develop specific strategies for addressing those inequities, including requiring states to develop equity plans for their HCBS programs, providing TA and funding for outreach to Black, Indigenous, and other communities of color, including non-native English speakers and LGBTQ+, and providers that serve them, and prioritize transition efforts in institutions disproportionately with residents from those communities.

Enhance 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.

- We believe HHS should prioritize strong implementation of the HCBS Settings Rule, including by providing additional guidance, technical assistance (TA) to states, and ongoing monitoring, with a focus on the heightened scrutiny process.
- Particularly in light of COVID19 laying bare the risks of institutional and large congregate settings, HHS should provide guidance on how states can expand community-based services and housing, further *Olmstead* implementation in their Medicaid systems, and work with the Department of Justice to support their *Olmstead* enforcement activities.
- Work with states and stakeholders to develop strategies to address workforce shortages in Medicaid HCBS programs. Currently, the essential workforce that provides HCBS is severely underpaid due to inadequate Medicaid rates paid to providers. The result is a community service delivery system that a survey of over 3,000 providers in 26 states indicates is challenged by high direct care vacancy rates and an average turnover rate of 43%, with numerous states reporting turnover in excess of 50%.
- We support enhancing states' ability to implement Medicaid 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. We urge CMS to finalize and work with states to implement core quality measures for HCBS that emphasize person-centered services, compliance with the HCBS Settings Rule, equity in access to HCBS, and best practices. As previously mentioned, we recommend HHS adopt the "CMS Meaningful Measures" approach, with the addition of HCBS and LTSS.

Ensure 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.

- We urge the Administration to direct resources to support multidisciplinary clinics to support patients and provide expert care to those with Post-Acute Sequelae of SARS-CoV-2 infection (PASC), myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), and other similar conditions. Multidisciplinary post-COVID clinics that can act as a comprehensive care center, providing access to multiple physician specialists, therapists, psychiatric services, and social work seem to be best at helping patients not only recover, but better understand their new diagnosis. These multidisciplinary clinics have started opening in academic medical centers, which have resources to support them, but are not available throughout the country.
- We urge HHS to use its leadership position and budgetary resources to ensure that this focus on Long COVID includes and benefits people with similar chronic illnesses, such as Chronic Fatigue Syndrome/Myalgic Encephalomyelitis, fibromyalgia, and dysautonomia, that have long gone under-diagnosed, under-researched, and under-treated, with devastating impacts on quality of life for people with these disabilities.

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

- We support HHS's strategies to improve data collection. In addition to key demographics HHS has identified, we recommend data collection also include residential setting and treatment setting.
- Having more comprehensive, directly collected data, and examining how the demographics intersect, will enable HHS to better identify compounding disparities for people with disabilities in access to and quality of care, services and supports.
- During the COVID-19 pandemic, people with disabilities, particularly those living in congregate settings, have faced higher risk of morbidity and mortality, often due to a conglomeration of risk factors: the hands-on nature of the services they need, the lack of effective protective equipment, and labor practices that often led to high turnover and staff interacting with multiple enrollees and increasing exposure risk. We also suspect, though there is little data, that people of color with disabilities have been especially hard hit by COVID-19. This attention to data is desperately needed both immediately to ensure that the COVID-19 response is addressing the needs of the disability community and all people, and longer term to move forward on building more equitable systems for delivering health care and long term services and supports.

Thank you for your time and attention. For more information, please contact Caroline Bergner, Director, Health Care Policy, Medicaid, for the American Speech-Language-Hearing Association at cbergner@asha.org and Natalie Kean, Senior Staff Attorney for Justice in Aging at nkean@justiceinaging.org.

Sincerely,

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November 7, 2021

U.S. Department of Health and Human Services
Office of the Assistant Secretary for Planning and Evaluation, Strategic Planning Team
Attn: Strategic Plan Comments
200 Independence Ave., SW, Room 434E
Washington, DC 20201

RE: DRRC Comments on Draft HHS Strategic Plan Fiscal Years 2022 – 2026

Strategic Planning Team:

On behalf of the Disability and Rehabilitation Research Coalition (DRRC), we appreciate the opportunity to comment on the Department of Health and Human Services' (HHS) draft Strategic Plan for Fiscal Years 2022 – 2026. The DRRC is a coalition of more than more than 25 national research, clinical, and consumer non-profit organizations committed to improving the science of rehabilitation, disability, and independent living. The DRRC seeks to maximize the return on the federal investment in these areas with the goal of improving the ability of Americans with disabilities to live and function as independently as possible following an injury, illness, disability, or chronic condition. The coalition plays a leadership role in coordinating the activities of stakeholders to increase and leverage federal resources devoted to research and development in these domains.

I. Overarching Comments

The DRRC fully supports President Biden's executive order on equity, diversity, and inclusion. EO 13985, *Advancing Racial Equity and Support for Underserved Communities Through the Federal Government*, defines equity as the "consistent and systematic fair, just, and impartial treatment of all individuals, including individuals who belong to underserved communities that have been denied such treatment, such as Black, Latino, and Indigenous and Native American persons, Asian Americans and Pacific Islanders and other persons of color; members of religious minorities; lesbian, gay, bisexual, transgender, and queer (LGBTQ+) persons; persons with disabilities; persons who live in rural areas; and persons otherwise adversely affected by persistent poverty or inequality."

We applaud the recognition that the government's goal in advancing equity is "to provide everyone with the opportunity to reach their full potential." We also support the directive that "each agency must assess whether, and to what extent, its programs and policies perpetuate systemic barriers to opportunities and benefits for people of color and other underserved groups

(which includes people with disabilities),” and the assertion that “such assessments will better equip agencies to develop policies and programs that deliver resources and benefits equitably to all.” We thank the Strategic Planning Team for recognizing the importance of these goals, and for incorporating the full scope of the executive order’s language throughout the draft Strategic Plan. It is critical that people with disabilities are recognized as an underserved population facing health and societal inequities, and that federal policy be cognizant of the disparities faced by the disability population and other underserved groups.

People with disabilities have always faced structural inequities in health (and access to health care), employment, community participation, and numerous other aspects of society. These disparities are widely recognized by the federal government, stakeholder organizations, and the general public. Despite this broad awareness, some components of HHS do not fully account for this aspect of health equity discussions. For example, people with disabilities are not designated as a U.S. health disparity population by the National Institutes of Health (NIH) and the National Institute on Minority Health and Health Disparities (NIMHD), an omission that the DRRC has long sought to resolve. Incorporating language recognizing the disability population throughout the HHS Strategic Plan is an important first step to ensuring that this population is appropriately considered in HHS policy over the next five years, and we thank the Strategic Planning Team for this inclusion.

We offer our comments below on the proposed strategic objectives, as well as major themes of interest to the DRRC in the draft plan, which cut across sectors of the plan.

Proposed Strategic Objectives

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

- People with disabilities are the heaviest users of health care, and therefore are particularly vulnerable to gaps in insurance coverage, barriers to access, and high cost. Targeted investments in primary and preventive services, adaptive and assistive technologies, and health education could vastly improve health outcomes within this population, and reduce long-term rates of comorbidity, hospitalization, institutionalization, and premature death. Such investments, of course, will not exclusively benefit the disability population; the health care system becomes stronger when these efforts are enhanced nationwide.

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

- People with disabilities are especially vulnerable during disasters and public health emergencies, and to the adverse impacts of climate change. The needs of the disability community must be explicitly included in all Departmental planning efforts, and any agency or office conducting preparedness efforts should examine and undertake inclusive disaster planning as a key priority.

Strategic Goal 3: Strengthen Social Well-Being, Equity, and Economic Resilience

- We are pleased to see that the draft Plan explicitly recognizes the critical importance of education, work, and independent living for the health and well-being of all individuals and

families, regardless of disability status. However, the artificial distinction between older adults and people with disabilities can impede disability research and program/policy development. The likelihood of having a disability increases with age, but people with disabilities have many of the same medical, social, and economic needs across the lifespan.

- We particularly appreciate the support for people with disabilities and disability researchers within this goal, especially 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.*”) However, we encourage the Department to revise the language of Strategy 1 (“*Enhance 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.*”) to more decisively support availability of and equitable access to home- and community-based support services for all individuals with disabilities, regardless of age.

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

- People with disabilities should be explicitly included throughout all stages of HHS-sponsored research, including project planning and prioritization, data collection and analysis, interpretation, dissemination, and utilization.

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

- The Department should coordinate disability research efforts with other federal agencies (such as the Departments of Education, Transportation, Labor, Justice, and Housing) under the authority of the Interagency Committee on Disability Research (ICDR), with the leadership of the Secretary of Health and Human Services as the statutorily appointed chair of this body.

Standardized Disability Data Collection

We greatly appreciate the Plan’s recognition of the importance of robust demographic data collection, especially disability status data. Demographic data collection is critical to advancing equity, not only to support traditional research endeavors, but to better identify and understand the disparities and inequities faced by people with disabilities and other underserved populations. Furthermore, accurate and comprehensive data, disaggregated by disability status and other demographic factors, allows policymakers and other stakeholders to more appropriately develop and evaluate policy solutions addressing the needs of people with disabilities.

The COVID-19 pandemic has laid bare and, in many cases, exacerbated not only the health disparities and inequities that these populations face, but the inadequacies of the current data collection regime at the federal, state, and local levels. For too long, there has been a lack of reliable information on how people with disabilities are impacted by any number of factors. During the pandemic in particular, it has been incredibly difficult to accurately gauge the extent to which people with disabilities are facing disproportionately higher risks of COVID-19 exposure, infection, serious and life-threatening symptoms, hospitalization, and death. The gaps

in disability data collection are replicated to varying degrees across other demographic categories as well. It is also critical to understand the intersectionality of race, age, disability, geography, chronic illness, and other identities; without improved data collection including disability status, the impact of these intersections will remain opaque.

Unfortunately, we have seen that far too often, disability communities are omitted from critical policy discussions around demographic data and the social determinants of health, or only included as an afterthought. The DRRC has called on the Administration and Congress to ensure that disability status is explicitly recognized as a mandatory category for demographic data collection across all federal efforts. We thank the Strategic Planning Team for recognizing this need and including disability status throughout the draft Plan and hope all offices within HHS take this inclusion into consideration as they carry out future efforts.

HHS Proposed Language:

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

Strategy 2: Remove barriers to healthcare access to advance health equity and reduce disparities

As noted above, people with disabilities face disproportionately high barriers to accessing health care across a variety of domains. We encourage HHS to explicitly recognize these barriers under this objective, and propose the addition of a new strategy, such as “*Identify and ameliorate environmental, institutional, and attitudinal barriers to appropriate and affordable healthcare for people with disabilities, including accessible healthcare facilities and equipment, transportation services, health literacy, and communication resources.*”

Strategy 3: Understand barriers to access and the impacts of social determinants of health to develop evidence-based, community-based healthcare service delivery models.

- ***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.***

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

Strategy 3: Support, conduct, and translate research into interventions that improve the health and well-being for all.

- ***Identify and address barriers to collaboration and data sharing within HHS and other federal agencies, academic and public health partners, and private industry to make it easier to conduct cross-cutting, high impact, transdisciplinary, innovative research.***

One of the primary barriers to data sharing across federal agencies is the lack of a standardized set of demographic data elements. By incorporating disability status explicitly throughout the Strategic Plan, and hopefully throughout the policies of all program operating components within

the Department, research efforts will be able to contribute uniformly to a fuller understanding of how various interventions, treatments, and programs impact different communities.

Additionally, we encourage the Department to more strongly support coordination of efforts within the agency in order to maximize the impact of research particularly in the areas of disability, independent living, and rehabilitation research. Existing federal bodies are already tasked with advancing these goals, but too often are under-staffed, under-resourced, and are limited to tackling “low-hanging fruit” rather than high-level, transformative efforts that would more fully encompass the Department’s aims as laid out in this draft Plan. Placing a Department-wide emphasis and focus on the work of bodies such as the ICDR would help better achieve these objectives and better serve the communities they are tasked with supporting.

The ICDR was established to promote coordination and collaboration among federal agencies conducting disability, independent living, and rehabilitation research. Under the Workforce Innovation and Opportunity Act (WIOA), the Secretary of Health and Human Services is named as the Chair of the ICDR in legislation, a role which has typically been delegated to the Director of the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR). We urge the Secretary and all Departmental members of the ICDR to recognize the important role this Committee plays in the coordination of critical research in these areas, and to make the necessary commitments of time, resources, and high-level staff to implement the duties of this body. Such commitment to the work of the ICDR will further the Department’s goal of conducting “cross-cutting, high impact, transdisciplinary, innovative research.”

Furthermore, the President’s Executive Order 13895 established an Interagency Working Group on Equitable Data, intended to identify “inadequacies in existing Federal data collection programs, policies, and infrastructure across agencies,” and to develop and support the implementation of strategies for addressing those deficiencies. We urge the Department to embrace the mission of this Working Group and partner closely with the rest of the Administration to ensure that each agency invests in the removal of barriers to collaboration and data sharing, especially regarding data that can be used to further the President’s goals of advancing equity for underserved populations.

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

Strategy 1: Establish a Department-wide approach to improve data collection, close data gaps, transform data, and share data for better HHS analysis and evaluation

- ***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.***

As outlined above, we strongly support this objective and, in particular, the full implementation of Section 4302 of the Affordable Care Act. It is past time for all HHS national data collection efforts to fully capture all relevant demographic data and provide a more complete understanding of how existing health policies, programs, disparities, and inequities impact different populations.

As the Department works to carry out this work under the updated Strategic Plan, the DRRC offers our members as a resource for technical assistance to implement these data collection efforts, especially regarding disability status. We encourage the Department to call upon the broad network of stakeholders and experts in the field, including individuals with lived experience, to ensure that data collection is representative of the target populations the Department seeks to quantify.

Strategy 3: Improve data collection and conduct evaluations to understand the drivers for inequities in health outcomes, social well-being, and economic resilience

- ***Better engage and include community stakeholders and those with lived experience into the policymaking, program improvement, and research processes.***
- ***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.***

Including community stakeholders in data collection and research efforts is absolutely critical to the accomplishment of the goals set out in the President’s executive order. DRRC has previously called on all Institutes and Centers within NIH to adopt the community engagement requirements used by NIDILRR and the Patient-Centered Outcomes Research Institute (PCORI). We encourage the Department to consider adopting similar guidelines across all agencies and offices conducting research and data collection to ensure participation and engagement from the disability population and other underserved communities. It is time that many or most (if not all) research studies undertaken under the Department’s authority should include a relevant, representative, and diverse body of stakeholders in research development, data collection, analysis and interpretation, and the dissemination and utilization of research findings.

As the Department continues to expand research and data collection relating to demographic categories and social determinants of health, it is also critical to recognize the intersection between these identifies. Demographic “boxes” do not operate in a vacuum. For example, research indicates that there are particularly high rates of disability within racial and ethnic minority populations. Recognized health disparity populations, including African Americans, American Indians, Alaska Natives, older adults, women, residents of rural and frontier communities, and people with low incomes and/or education levels, also have significantly higher rates of disability. The intersection of minority identities, including disability, should be recognized as an overarching and critical dimension of health and health care disparities. All equity-focused efforts within the Department, should take intersectionality into account and ensure that all minority populations are recognized, represented, and equitably served.

Disability Inclusion in Workforce Programs

HHS Proposed Language

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.

Strategy 2: Recruit, retain, and develop a diverse and inclusive scientific workforce to conduct basic and applied research in disease, healthcare, public health, and human services.

- **Expand and deploy 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.**
- **Increase 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.**

Research in the health care field should reflect the population which the research aims to serve. DRRC believes that the biomedical research workforce should more fully represent the broader population, especially those which research aims to serve. The Department should prioritize diversity, equity, and inclusion among its own workforce, research grantees, clinical trial participants, public advisors, and the stakeholder groups with which the Department engages, including individuals with disabilities. We encourage the Department to explicitly include language around scientists with disabilities in this section of the Plan.

It is also critical that diversity and inclusion efforts at HHS, especially within the agencies conducting health research, address training and mentorship programs particularly for individuals with disabilities and chronic conditions – not only for research relating to disability, but throughout the broader scientific workforce. We urge HHS to develop and fund, through its program operating components, pre-doctoral and post-doctoral training programs for researchers with disabilities, and to encourage grant applicants to disclose the disability status of team members. HHS should also ensure that mentorship programs supported by the Department are inclusive of individuals with disabling conditions, both among the mentor and mentee populations.

We further urge HHS to prioritize patient engagement across Departmental efforts. Modern research practice recognizes the importance of breaking down the divisions between researchers and their subjects to create more equitable, generalizable, meaningful, and translatable research. As stated above, the Department should consider adopting robust community engagement requirements to guide its research efforts and include relevant stakeholders. Supporting a diverse and inclusive workforce will not only begin to combat long-existing barriers to access and inequities in the biomedical research pipeline but will lead to more responsive research and dissemination strategies and maximize the impact of HHS' critical work for all populations.

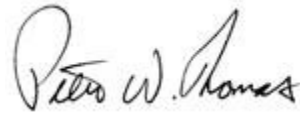
We greatly appreciate your consideration of our comments, and we look forward to continuing to work with the leadership of the Department and its program operating components over the next five years and beyond. Should you have any further questions, please contact the DRRC coordinators at Peter.Thomas@PowersLaw.com, Joseph.Nahra@PowersLaw.com, and Bobby.Silverstein@PowersLaw.com or by phone at 202-466-6550.

Sincerely,

The Disability and Rehabilitation Research Coalition



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