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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: HHSPlan@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

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[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/.

[2] Hall JP, Shartzer A, Kurth NK, Thomas KC. Medicaid Expansion as an Employment Incentive Program for People With Disabilities. Am J Public Health. 2018 Sep;108(9):1235-1237. doi: 10.2105/AJPH.2018.304536. Epub 2018 Jul 19. PMID: 30024794; PMCID: PMC6085052.

[3] Hall JP, Shartzer A, Kurth NK, Thomas KC. Effect of Medicaid Expansion on Workforce Participation for People With Disabilities. Am J Public Health. 2017 Feb;107(2):262-264. doi: 10.2105/AJPH.2016.303543. Epub 2016 Dec 20. PMID: 27997244; PMCID: PMC5227925.

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.

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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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