NACDD
National Association of Councils on Developmental Disabilities

October 26, 2017

Office of the Assistance Secretary for Planning and Evaluation
Strategic Planning Team
Department of Health and Human Services
200 Independence Ave. S.W.
Room 415F
Washington, D.C. 20201

VIA ELECTRONIC MAIL – HHSPlan@hhs.gov

RE: HHS Strategic Plan Comments

The National Association of Councils on Developmental Disabilities (NACDD) appreciates this opportunity to comment on the Department of Health and Human Services (HHS) Strategic Plan. NACDD is the national membership association for the 56 State Councils on Developmental Disabilities (DD Councils). NACDD supports the DD Councils in implementing the Developmental Disabilities Assistance and Bill of Rights Act (DD Act) and promoting the interests and rights of people with developmental disabilities and their families. Located in every State and Territory, DD Councils bring together individuals with disabilities, family members, state agency personnel and others who work to improve full access to the community. The Governor appoints citizen members of the Councils. At least 60% of DD Council members are people with developmental disabilities or family members.

NACDD is generally pleased to see that HHS's strategic plan addresses issues related to individuals with disabilities. We support provisions throughout the plan that recognize accessibility, community-integration and self-determination are implicated in any discussion of health care. People with disabilities want to live, learn, work, pay taxes, and be productive and fully included in their communities.

Strategic Plan Goals for Organizational Structure

NACDD recognizes that change is sometimes necessary. However, any changes to organizational structures must not be contrary to the goals of the DD Act. In particular, NACDD and the DD Councils support the current way ACL structures federal investment in the DD Act. The DD Act has been effective and efficient in improving the service delivery system for persons with developmental disabilities for over 47 years. NACDD is working with Congress to continue the current funding and structure of the DD Act.

NACDD has worked within the ACL structure efficiently and effectively to meet mutual goals of recognizing the "fundamental principle that older adults and people with disabilities of all ages should be able to live where they choose, with the people they choose, and with the ability to participate fully

in their communities."[1] While the goals of the DD Act may seem similar to other populations of people with disabilities, the DD Councils were created to ensure that individuals with developmental disabilities are fully considered in the design and implementation of services and supports within the state. DD Councils will be unable to meet this purpose in creating them with consolidation and reduced funding in the ACL structure.

Strategic Plan Implications for People with Disabilities

HHS's strategic plan appropriately addresses issues related to individuals with disabilities throughout the entire plan, recognizing that accessibility, community-integration and self-determination are implicated in implicated in almost every aspect of health care. Our comments below seek to clarify and strengthen HHS' strategies to promote the following four goals: expansion of access to services in the context of behavioral and physical health collaborative models; promotion of community-integration and inclusion; protection of the right to person-centered services and self-determination; and protection all other individual rights.

We appreciate HHS' commitment to promoting collaborative models of behavioral and physical health care. Such collaboration has the potential to both address shortages of behavioral health professionals via consultative models, and to address unmet physical health care needs of individuals receiving behavioral health care services. To the extent these models focus on the former by expanding the reach of behavioral health professionals via screening, telemedicine, and/or other consultative models, HHS should ensure that such approaches are coupled with an explicit commitment to expanding and integrating essential community-based behavioral health support services. Essential community-based services include, but are not limited to, Peer Support Services, Assertive Community Treatment, Mobile Crisis Intervention, and various other intensive community-based services.

Last, we appreciate HHS' acknowledgment that some of the barriers to treatment pursuant to HIPAA may be "perceived barriers." As HHS investigates such barriers, we encourage HHS to promote solutions that protect individual privacy while promoting self-direction and advanced planning. Advance directives for behavioral health care (also known as psychiatric advanced directives) are one such legal tool which allow individuals to designate types of treatment and settings in which they want to receive care, and allow them to designate certain individuals or providers that should be notified regarding treatment needs.

Here are some additional comments related to these issues:

- We appreciate that HHS has included a section regarding improving Home and Community-Based Services (HCBS), and that HHS makes explicit mention of the well-established and crucial right to community integration and inclusion in numerous sections of the strategic plan. While we encourage the development of additional community supports to enhance community integration, we caution against relying on such supports in place of paid supports.

- Choice of providers for mental health and substance use treatment services is often quite limited. Care must be taken to ensure that all individuals are able to access care free of discrimination.

[1] Administration for Community Living. https://www.acl.gov/ (October 25, 2017).

- HHS' commitment to protecting individual rights and addressing abuse and neglect should be clarified to ensure it is clearly applicable in all facilities where individuals with disabilities receive services, not just in traditional health care settings.

- Protection from abuse and neglect must be built into emergency planning. People with disabilities and older adults too often bear the brunt of poor disaster planning, and may need additional assistance to safely survive emergencies.

- We object to HHS' characterization of a lack of "personal responsibility" as the barrier to employment for returning citizens, without acknowledgement of discriminatory hiring practices, disability and/or trauma and restrictive conditions of release as major reasons for unemployment. Reentry support should be a long-term investment that addresses both structural and individual barriers to work.

Implications for Individuals with Disability Experiencing Multiple Forms of Discrimination

Disability rights are human and civil rights. Although many people find it difficult to see beyond disability, as it causes an immediate reaction and has many stereotypes attached to it, people with disabilities experience discrimination based on multiple aspects of their identity, such as race, ethnicity, gender, age and sexuality.

HHS must continue to undertake activities to identify and address health disparities with the ultimate goal of eliminating them. In activities spanning the Office for Civil Rights, Office of Minority Health, Office of Women's Health as well as the Centers for Medicare & Medicaid Services, all of HHS' endeavors must ensure that disparities are not heightened but are prevented. We appreciate recognition of the need to address disparities within the Strategic Plan but believe that HHS must strengthen these sections to ensure all individuals can achieve their health equity.

Further, the Strategic Plan should ensure that all of HHS' activities are undertaken in a culturally competent manner. Providing culturally competent services is critical to ensure that services are client/patient centered and are appropriate for not just the particular program at issue but also for the clients/enrollees served. We urge HHS to include more specific and measurable goals and strategies to address cultural competency in a holistic manner including race, ethnicity, language, immigration status, age, disability, sex, gender identity and sexual orientation.

Here are some additional comments related to these issues:

- We support HHS' recognition of the need for health literacy tools. We suggest HHS specifically recognize the need to provide culturally competent tools such that all individuals, regardless of their background, can benefit from these tools.

- We recommend additional requirements to specifically address collecting, analyzing and applying ***demographic*** data.

- We appreciate HHS's mention of the need to reduce disparities. We believe this includes not merely racial and ethnic health disparities but also disparities based on language, age, sex,

sexual orientation, gender identity, and disability. We recommend HHS include a broad definition of health care disparities in its strategic plan.

- We note that alternative payment models must not be implemented in such a way that they create incentives to stint on needed care or avoid costlier patients. We believe that HHS should focus on models that prioritize primary care (for example, that include strong PCMH requirements). Furthermore, we recommend that if HHS uses financial incentives, those incentives should be focused on improving outcomes and not to reducing costs.
- We appreciate the recognition of the need to provide programs that improve the quality of care and increase access. To that end, we recommend that such programs be developed and implemented in a culturally competent manner.
- We strongly support the inclusion of the strategy "Reduce disparities in quality and safety" as it is critical to ensure that our health care system is accessible to all individuals, regardless of race, ethnicity, language, immigration status, sex, gender identity, sexual orientation, age and/or disability.
- To the extent HHS recognizes the need for providing materials in non-English languages, HHS should also recognize the need for providing materials in formats that will be accessible to individuals with disabilities who have communication needs. This would include large print format and audio or video recordings for those who cannot access written materials.
- We are concerned that the plan fails to mention other federal civil rights laws and Executive Orders which are relevant to providing healthcare options that are responsive to consumer demands. These include Executive Order 13166, Title VI of the Civil Rights Act of 1964, Section 504 of the Rehabilitation Act, the Americans with Disabilities Act, the Age Discrimination Act, and Section 1557 of the Affordable Care Act. All of these laws must be fully implemented and enforced by HHS to ensure that HHS' programs and activities, and those it supports with federal funds, are responsive to consumer demands.
- We do not agree with HHS's statement that removing barriers to and promoting participation in HHS programs by persons and organizations with religious beliefs or moral convictions is a solution to assisting targeted populations. Rather, HHS should remain religiously and morally neutral in its funding and activities to ensure that individuals do not feel proselytized by providers or receive access to a limited scope of services due the moral or religious nature of an organization.
- We appreciate the role HHS has in preparing for and responding to public health emergencies. We believe that much of this work, especially in the provision of tools to states and providing public health communications must be done in a culturally competent manner.
- We support the recognition of the need to improve collaboration with State, Local, Tribal and Territorial (SLTT) partners. We recommend that these strategies also specifically recognize the need to provide information in a culturally competent manner.

- We support the objective to optimize information technology investments to improve process efficiency and believe HHS should ensure that efforts to identify and address healthcare disparities are sufficiently recognized and address with regard to information technology investments.
- We recommend HHS revisit the Strategic Plan taking into consideration the large body of research demonstrating the need for specific and competent inclusion of LGBT people in all aspects of efforts to improve the health of Americans.

Impact on People with Substance Use Disorders

We appreciate HHS' recognition of the importance of expanding the entire spectrum of interventions, from prevention through recovery, as well as the importance of public health approaches to preventing, identifying, and treating substance use disorders. We also support the emphasis on a collaborative approach that involves both governmental and non-governmental organizations.

We recommend specific goals to address the unique concerns of children born with disabilities or children who manifest physical or mental impairment as a result of substance abuse by the parent should be a critical part of the strategic plan. Additionally, we urge HHS to engage in education and outreach to ensure that both governmental and non-governmental organizations are aware of and are utilizing modern, evidence-based, non-stigmatizing approaches to substance use disorders. We also urge HHS to ensure that "community" organizations are inclusive of people who use drugs (PWUD), including harm reduction organizations.

Additional Comments

We believe HHS' strategic plan must specifically mention and address HHS' legal responsibility to uphold the laws of the United States, including the Affordable Care Act and Medicaid. Without robust implementation of the ACA and adherence to Medicaid's governing statute and regulations, many of the goals and strategies outlined in this plan will be unobtainable. Further, we appreciate the recognition that consumers and enrollees should have choice but that choice must come with sufficient knowledge and information to make informed choices. The recent actions by the Administration to cut funding for navigators and open enrollment outreach are contrary to the stated ability to provide consumers with choices that they actually can understand. Navigators in particular play a critical role in informing consumers about their eligibility for health insurance, helping them enroll, explaining how to use health insurance, and connecting them with health care.

We thus suggest adding a new "strategy" bullet that would read as follows:

"Implement and enforce the ACA

- Ensure sufficient resources to maintain and improve healthcare.gov and its Call Center.
- Provide sufficient financial support to FFM navigators to ensure they can operate in all counties in all FFM states and throughout the entire calendar year.
- Conduct outreach activities commensurate with the need to educate and inform individuals about the marketplaces, public health insurance programs (including Medicaid, CHIP and Medicare), their health insurance options, and how to enroll.

- Ensure compliance with all statutory and regulatory requirements regarding the Affordable Care Act and Medicaid."

Thank you for your attention to our comments. If you have any questions or need any further information, please contact Erin Prangley, Director, Public Policy at eprangley@nacdd.org or (202)506-5813 x104.

Sincerely,

Erin Prangley
Director, Public Policy
National Association of Councils on Developmental Disabilities