DRRC
Disability & Rehabilitation Research Coalition

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.

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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,

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