



December 6, 2022

The Honorable Chiquita Brooks-LaSure
Administrator, Centers for Medicare & Medicaid Services (CMS)
7500 Security Boulevard
Baltimore, MD 21244

Re: CMS-0058-NC

Administrator Brooks-LaSure:

We, the undersigned members of the Consortium for Constituents with Disabilities (CCD) Health Task Force write in response to the Request for Information(RFI): National Directory of Healthcare Providers & Services (NDH).

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. The CCD Health Task Force works to ensure access to high quality, accessible, affordable health care for people with disabilities and complex conditions of all ages that meets their individual needs and enables them to be healthy, live as independently as possible, and participate in the community. We work to promote access to comprehensive coverage and eliminate discrimination, disparities and inequities for people with disabilities within and across health care payers, providers, and systems. We recognize that racist and ableist structures, policies and practices have caused and continue to cause disproportionately worse outcomes for Black, Indigenous and other people of color with disabilities. And just as race and disability discrimination intersect, social determinants of health and compounding inequities related to age, size, national origin, immigration status, language, gender, gender identity, and sexual orientation, can further reduce access to care and community for people with disabilities. Our advocacy prioritizes recognizing such inequities and championing policies that will reduce and eventually eliminate them.

If CMS chooses to create an NDH, it is crucial that the directory include information that is useful and accessible to people with disabilities, including information on the accessibility and modifications made to provider offices. The directory and any instructions for using it should meet, at least, the requirements under Section 508 of the Rehabilitation Act for government websites and the information in the directory should be provided in plain language. Better still, we recommend compliance with the latest version of the Worldwide Web Consortium's Web Accessibility Initiative's Web Content Accessibility Guidelines, WCAG (WCAG Standards) at the AA level ("acceptable compliance") within one year of the latest update. The directory should also include information on the physical accessibility of offices and diagnostic equipment. Physical access should be defined as that the office meets the

standards for accessible buildings and accessible medical diagnostic equipment published by the US Access Board.¹

CMS should also include information on languages spoken and other accommodations available at the office. Despite federal requirements, many people with disabilities and/or limited English proficiency continue to face access barriers to health care.² All health providers which receive federal financial assistance are required to provide meaningful access for people with limited English proficiency and effective communication for people with disabilities. Providers should also make reasonable accommodations to their offices to ensure programmatic accessibility, such as adapting waiting room times for visits. However, not all providers adhere to these standards. For example, some providers may become hostile when asked to provide translators or make accommodations. Other providers are unwilling to treat people with disabilities.³ For these reasons, we encourage CMS to include information on languages spoken, accessible buildings and equipment, and other reasonable accommodations the office has undertaken, and we agree that CMS should include information on providers that have completed cultural competency training. Including such information will help prospective patients not only find accessible care, but also find a provider more likely to provide them with high quality care.

People with disabilities often need services from many different types of providers, including allied health professionals and suppliers of durable medical equipment. Existing provider directories also often include incorrect information or “ghost networks” – network directories that include providers that are not in-network or simply don’t exist – especially in mental health services.⁴ We believe that including accurate information on multiple types of providers in the NDH will facilitate access to these providers. In addition to the providers listed in the RFI, we encourage CMS to include providers of home- and community-based services (HCBS). While we recognize that including HCBS providers will be a challenge to a traditional provider directory, we encourage CMS to work with state Medicaid departments and the Administration for Community Living (ACL) on how to effectively implement this change. ACL’s Eldercare Resource Locator may be an effective tool here. Including HCBS in the NDH could address some of the institutional biases in the health care system by helping health care providers refer people to HCBS instead of nursing homes or other institutional services.

The health policy journal *Health Affairs* recently devoted their entire October issue to disability and health.⁵ The issue highlighted health disparities, lack of accessibility, and a lack of knowledge or willingness among health care providers to treat people with disabilities. One study based on physician focus group responses identified “apathetic and even adversarial” attitudes toward the ADA and

¹ See the guidelines for buildings <https://www.access-board.gov/ada/> and medical diagnostic equipment <https://www.access-board.gov/mde/>

² Lisa I lezzoni et al., Have Almost Fifty Years Of Disability Civil Rights Laws Achieved Equitable Care?, 41 Health Affairs 1371 (2022) <https://www.healthaffairs.org/doi/full/10.1377/hlthaff.2022.00413>

³ Tara Lagu et al., “I Am Not the Doctor for You”: Physicians’ Attitudes about Caring for People with Disabilities, 41 Health Affairs 1387 (2022) <https://www.healthaffairs.org/doi/full/10.1377/hlthaff.2022.00475>

⁴ Abigail Burman , Laying Ghost Networks to Rest: Combatting Deceptive Health Plan Provider Directories , 40 Yale L. & Pol’y Rev. 78 (2021). <https://ylpr.yale.edu/laying-ghost-networks-rest-combatting-deceptive-health-plan-provider-directories>

⁵ Health Affairs Vol. 41 No. 10, October 2022, Disability & Health <https://www.healthaffairs.org/toc/hlthaff/41/10>

widespread discomfort treating people with disabilities.⁶ This reinforces similar results from an earlier survey of US physicians that found poor awareness about the ADA, low confidence in treating people with disabilities, and low scores for welcoming people with disabilities into a practice.⁷ We hope that if CMS decides to pursue an NDH, it includes information important to people with disabilities to help them navigate the health care system and find health care providers ready to provide them with high quality care. We encourage CMS to review the barriers listed above, the entire Health and Disability issue of Health Affairs, as well as the National Council on Disability's Health Equity Framework for People with Disabilities⁸ when developing this directory and in other health equity efforts.

Thank you for the opportunity to provide information. For more information, contact Rachel Patterson at the Epilepsy Foundation at rpatterson@efa.org.

Sincerely,

Access Ready
American Association on Health and Disability
American Occupational Therapy Association (AOTA)
American Physical Therapy Association
American Speech-Language-Hearing Association
American Therapeutic Recreation Association
Epilepsy Foundation
Justice in Aging
National Association of Councils on Developmental Disabilities
The Arc of the United States
The Bazelon Center for Mental Health Law

⁶ Tara Lagu et al.

⁷ Lisa I lezzoni et al., Physicians' Perceptions of People with Disability and Their Health Care, 40 Health Affairs 297 (2021). <https://www.healthaffairs.org/doi/10.1377/hlthaff.2020.01452>

⁸National Council on Disability, Health Equity Framework for People with Disabilities, (February 2022) https://ncd.gov/sites/default/files/NCD_Health_Equity_Framework.pdf