April 30, 2022 *via Online Portal (*[*www.healthit.gov*](http://www.healthit.gov) *USCDI comment portal)*

National Coordinator Micky Tripathi

Deputy National Coordinator Steven Posnack

Office of the National Coordinator for Health Information Technology

Office of the Secretary, United States Department of Health and Human Services

**Re: Request for Public Comment, Draft United States Core Data for Interoperability (USCDI) v3**

Dear National Coordinator Tripathi and Deputy National Coordinator Posnack,

The Disability Rights Education and Defense Fund (“DREDF”) appreciates the opportunity to provide comment on the draft United States Core Data for Interoperability (USCDI) v3, released January 2022. DREDF is a national cross-disability law and policy center that protects and advances the civil and human rights of people with disabilities through legal advocacy, training, education, and development of legislation and public policy. We are committed to increasing accessible and equally effective healthcare for people with disabilities and eliminating persistent health disparities that affect the length and quality of their lives.

DREDF is deeply appreciative of the inclusion in USCDI v3 of three disability-related data elements within the new health status data class. We understand that the Health Information Technology Advisory Committee (HITAC) adopted at its April 13, 2022 meeting the [Interoperability Standards Workgroup Report to the Health Information Technology Advisory Committee](https://www.healthit.gov/sites/default/files/facas/2022-04-13_IS_WG_Phase_1_Recommendations_Report_revised.pdf), including its recommendations for changes to USCDI v. 3 that will be incorporated in the final USCDI report which will be issued in July 2022. Our comments on this letter are directed toward, and support, the detailed recommendations made in the Interoperability Standards Workgroup Report which we anticipate will be incorporated in the final USCDI.

The inability to identify people with disabilities as a distinct *and* heterogenous group that receives healthcare has been a longstanding problem, directly affecting both the quality of healthcare received by people with various disabilities and exacerbating the difficulty of establishing that disabled persons are subject to health and healthcare disparities that cannot and should not be attributed simply to the presence of a disability. In particular, the lack of demographic data on the specific functional limitations experienced by patients with disabilities has compounded these two issues of healthcare quality and healthcare *in*equality. A diagnosis code, in and of itself, does not capture an individual’s functional limitations for a variety of reasons (e.g., progressive conditions where a varied potential set of functional limitations appear at different rates and under different conditions for individual patients, idiopathic and rare conditions with functional impacts that cannot be easily predicted, and so forth). On the other hand, detailed clinical information about an individual’s medical conditions and symptoms cannot be easily and quickly used by frontline provider staff, across a wide variety of patient disabilities and chronic health conditions, to ensure that individual patients receive effective care.

Ensuring Effective Care for People with Disabilities

An electronic health record that lacks functional limitation information such as those captured within the 6 disability questions used in the American Community Survey and other national surveys administered by the U.S. Census Bureau means that healthcare providers lack critical information needed to provide effective care to disabled patients. When providers and staff do not know that a patient cannot independently transfer to exam tables without assistance they can be scheduled in inaccessible rooms with inaccessible equipment, individuals who need sign language will face wasted time and require another appointment if they cannot receive appropriate interpretation, and individuals with developmental disabilities will not be provided with additional time. Similarly, a person with communication disabilities who does **not** have intellectual disabilities, which is a common stereotyped assumption, will be treated inappropriately by staff and providers. These commonly occurring problems directly affect whether and how people with disabilities receive common preventive tests and care, as well as informed and timely healthcare. The inclusion of functional demographic information allows providers to begin to note and understand how to provide effective care to PWD, and will allow providers to begin to work together with advocacy groups to demand health IT systems that allow recording accommodation information, and flag that information so it can be consistently provided and updated over time, even as patient needs change.

Ensuring Equitable Care for People with Disabilities

President Biden’s emphasis on health equity in his [January 2020 Executive Order](https://www.federalregister.gov/documents/2021/01/25/2021-01753/advancing-racial-equity-and-support-for-underserved-communities-through-the-federal-government) supports the need for disability information that captures voluntary self-identification of functional limitations.[[1]](#footnote-1) The [Office of the National Coordinator has explicitly recognized](https://www.healthcareitnews.com/news/oncs-top-goals-interoperability-alignment-and-equity) the President’s call to action and the important role that Health IT can assume in “health equity by design.”[[2]](#footnote-2) The incorporation of disability status **as a demographic factor** in electronic health records will allow researchers, advocates, and public health experts to recognize and explore the full contours of health inequities and disparities experienced by people with disabilities, whether those barriers are based in inaccessible structures or equipment for people with mobility disabilities, the failure to provide alternative formats to blind individuals or sign language to Deaf persons, a lack of knowledge about the health needs of people with developmental disabilities,[[3]](#footnote-3) or stereotypes and assumptions about capacity and quality of life for people with significant disabilities.[[4]](#footnote-4)

The experience of people with many different disabilities during the pandemic vividly illustrates the problem. The failure to identify people with disabilities demographically left advocates unable to identify how COVID-19 affected this population group. We could not identify how many people with disabilities in the community and outside of institutions, where the great majority of people with disabilities live, were infected, were hospitalized, and died from COVID. We could not illustrate with data how a lack of mobility or blindness affected the capacity to book a vaccination appointment or receive vaccination. We were unable to illustrate the elevated risks that people with disabilities faced from the virus when they needed personal care assistance in their homes. As a matter of clinical need, people with disabilities such as vision, intellectual, or speech disabilities that affected how they could respond to such medical mortality tests as the Glasgow Coma Score would not necessarily have that information in their electronic health records, leaving people with disabilities and their families terrified of ending up in an emergency room and unable to fully indicate their capacity to respond to treatment should care be triaged during a surge situation.

Conclusion

In summation, DREDF strongly supports the inclusion of the three disability elements recommended for inclusion in USCDI v3, including clinical information on functional status and mental/cognitive status. DREDF also strongly supports the Interoperability Standards Workgroup’s recommendation to expand on the Sexual Orientation and Gender Identity elements that were already included in USCDI v2 by incorporating the five data elements recommended by the Gender Harmony Project. These additional elements will expand the capacity of providers to provide informed care and solicit medically relevant information in ways that reflect the vocabulary and self-identification of LGBTQ+ individuals. We further recognize and recommend that non-binary gender identity/categorization incorporate language such as “Two-Spirit” which is used by Native American and other indigenous groups.

Thank you again for the opportunity to comment on USCDI v3. Please do not hesitate to contact Silvia Yee at syee@dredf.org if you have any questions about the above.

Sincerely,

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Silvia Yee

Senior Staff Attorney

1. Executive Office of the President. Executive order 13985: Advancing racial equity and support for underserved communities through the federal government. Washington, DC: The White House, January 20, 2021. [↑](#footnote-ref-1)
2. Jercich K, “ONC’s top goals: Interoperability, alignment, equity.” Health IT News. March 29, 2021. [↑](#footnote-ref-2)
3. These and other examples of the kinds of disparities experienced by people with disabilities have been increasingly documented in research that includes Yee, Breslin, et al., Compounded Disparities: Health  Equity  at  the  Intersection  of  Disability,  Race,  and  Ethnicity, National Academies of Sciences, Engineering, Medicine, published April 13, 2018, at <https://www.nationalacademies.org/our-work/the-intersections-between-health-disparities-disabilities-and-health-equity-a-workshop>; Krahn G.L., *et al.*, Persons with disabilities as an unrecognized health disparity population.  Am J Public Health. 2015; 105:S198-206. doi:10.2105/AJPH.2014.302182. [↑](#footnote-ref-3)
4. Lisa I. Iezzoni *et al.*, Physicians’ Perceptions of People with Disability and their Health Care, November 2021, available at https://www.healthaffairs.org/doi/10.1377/hlthaff.2020.01452 (in survey of 714 practicing US physicians nationwide, 82.4 percent reported that people with significant disability have worse quality of life than

nondisabled people. Only 40.7 percent of physicians were very confident about their ability to provide the same

quality of care to patients with disability, and just 56.5 percent strongly agreed that they welcomed patients with

disability into their practices). [↑](#footnote-ref-4)