



*For people with intellectual  
and developmental disabilities*

June 26, 2023

The Honorable Micky Tripathi, PhD, MPP  
National Coordinator for Health Information Technology  
Office of the National Coordinator for Health Information Technology  
U.S. Department of Health and Human Services  
330 C St SW; Floor 7  
Washington, DC 20201

Re: United States Cored Data for Interoperability (USCDI) + Quality

Dear National Coordinator Tripathi:

We are writing to comment on the draft of USCDI+Quality from the Office of the National Coordinator for Health Information Technology (ONC) compiled from submissions to United States Core Data for Interoperability (USCDI) on behalf of The Arc of Massachusetts.

The Arc of Massachusetts is the leading advocacy agency on behalf of 200,000 persons with intellectual and developmental disabilities (I/DD) and their families. There are 17 chapters in our state and over 600 nationwide working together to advance the lives of persons with disabilities. Our mission is to enhance the lives of people with intellectual and developmental disabilities, including autism, and their families. We fulfill this through advocacy for *community supports and services* that foster social inclusion, self-determination, and equity across all aspects of society.

Present health data often excludes persons with disabilities or caregivers of persons with disabilities and the implications for health outcomes. We appreciate the inclusion of social determinants of health (SDOH) but often existing assessment tools do not capture key information affecting the health of persons or caregivers of persons with disabilities.

We request additional SDOH elements be included possibly under several classes:

1. Assessment and plan of treatment
  - a. Assessment and plan
  - b. SDOH Assessment
2. Clinical Notes
  - a. Discharge summary notes
3. Problems
  - a. SDOH problems/Health concerns
4. Procedures
  - a. SDOH interventions

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**Achieve with us.**

Janet Sweeney Rico, Ph.D.  
President

Leo V. Sarkissian  
Executive Director

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The Arc in Massachusetts Includes the Following Local Chapters:

Berkshire County • Bristol County • Greater Brockton • Center of Hope Foundation • Charles River Center • Communitas  
Community Connections • Greater Haverhill-Newburyport • Incompass HS • Lifeworks. • Minute Man • Northeast  
Opportunities for Inclusion • The Arc of Opportunity • Plymouth and Upper Cape • South Shore • The United Arc

Brief comments on extension of SDOH elements which exist or have been recommended by other respondents:

- (1) Housing Instability and Homelessness - child, teen or adult may represent additional responsibilities which have financial or other implications for a family
- (2) Inadequate Housing – caregivers and an individual(s) with disabilities may be living in inadequate housing given requirements of support needed for individual(s)
- (3) Transportation Insecurity – addressing associated health needs, requirements for attending school or specialized youth or adult services/programs
- (4) Financial Strain – inability of caregiver to work given responsibilities and/or additional costs that are not covered by insurance
- (5) Social Isolation – individuals with disabilities not receiving adequate supports, caregivers not able to respond appropriately; isolation of caregivers, individuals not having communication limitations, etc.
- (6) Stress – increased stress due to daily care needed by individual, 24/7 care of individual, lack of support system, individuals with disabilities increased stress due to lack of proper assessment, inappropriate services or ineffective behavioral approaches.

2. Following are the recommendations for expanded SDOH elements under one or more of the elements above:

1. Specific disability type
2. Care level
  - a. Throughout day
  - b. Daily
  - c. Throughout week
3. Isolation –
  - a. Communication skills
  - b. Lack of peer relationships
  - c. Need for and lack of daily services
4. Behavioral barriers- daily, weekly (harm to self or othera)

We believe that our comments require further discussion to better integrate recognition of what may appear as a specialized population among SDOH and the broad classes. It is estimated that one in four (1:4) people have disabilities in the United States. Given that fact better recognition is vital.

Thank you for the opportunity to provide these comments.

Sincerely,



Leo V. Sarkissian  
Executive Director