Road Map – Milestones for Advancing Knowledge on the Prevalence and Health Status of Individuals with Intellectual and Developmental Disabilities

***Vision:***

To develop a 2020–2030 Road Map that will advance a robust health surveillance system for people with intellectual and developmental disabilities (ID/DD) that is used to inform policies, programs, and projections. To do this, we will work in partnership with various groups to ensure the data collected, analyzed, and disseminated reflect partners interests, needs, and priorities.

***Goals:***

* + - * Identify people with ID/DD and describe more fully their health status using existing methods and data
* Identify data gaps on inequities in health status, and health care access and utilization

***Aims:***

1. Collaborative partnerships with stakeholders
2. Estimated prevalence and health status
3. Enhanced capacity for data access and analysis
4. Enhanced visibility through data utilization and dissemination

***Outcomes and Activities:***

1. **Enhanced partnerships with federal, state, and local partners for increased utilization of data**
   1. Recruit input from diverse stakeholders (persons with lived experience and families, health care professionals, researchers, state agencies and organizations, health care industry, federal agencies)
   2. Establish workgroups with partner input on select topics to determine best practices or strategies for improving data availability, analyses, and utilization and dissemination.
2. **Improved availability of nationally representative data** **about people with ID/DD:**
   1. Develop questions for inclusion in national surveys and get them added to the surveys
      1. Develop and pilot test questions that identify people with ID/DD on the National Health Interview Survey (NHIS) annual core questionnaire
      2. Implement question set on NHIS core
      3. Validate the ID/DD identifier questions
      4. Promote uptake of the identifier questions in other surveys (e.g., BRFSS, other federal surveys, state data sets)
   2. Ensure a consistent surveillance definition of ID/DD
   3. Standardize strategies for proxy- vs self-reporting on survey questionnaires
   4. Ensure on-going quality and accuracy of surveillance data
      1. Continue to validate the survey questions — conduct periodic validation studies to determine if we’re getting people with ID/DD with the questions
   5. Support capacity of researchers to analyze the data (e.g., building infrastructure and algorithms)
3. **Enhanced data access and analyses of State and other administrative data**
4. Engage with entities that have or use state and other administrative data on people with ID/DD and their health
5. Engage with insurers and other payors of health services on data availability and analyses on people with ID/DD
6. Enhance collaborations among State Developmental Disability Services, Developmental Disability Councils, University Centers for Excellence in Developmental Disabilities, Projects of National Significance in developmental disabilities, and Protection and Advocacy organizations to promote working together, and to establish guidelines for analyzing data for relative comparability across states. Explore use of learning collaboratives to promote such collaborations
7. Conduct survey of state practices and model analyses that is more complete than was possible through WorkGroup efforts in 2018
8. Consider need for a Coordinating Center of Excellence in ID/DD Health Data that would include promoting data collaboratives at the local, state/territory, regional levels to utilize available administrative data
9. Develop standards/guidelines for data analysis and communication regarding health of people with disabilities that address:
   1. populations included
   2. variable clarification
   3. align data elements for prospective data collection

d. capture race/ethnicity/language

g) Examine health status using administrative data

1. **Improved utilization and dissemination of data about health equity of people with ID/DD** 
   1. Increase utilization of data and research by the individuals with lived experiences, families, and other advocates by establishing standards and/or best practices for communicating and translating data, and disseminating cognitively accessible data briefs for different audiences (persons with ID/DD, legislators, advocacy groups, researchers):
      1. Develop communication plan for reaching out to key audiences, including legislators
      2. Develop multi-format/multi-channel communication — Explore mechanisms to reach target audiences (listservs, social media platforms, blogs, newsletters, disability and other advocacy groups)
      3. Translate data for use to improve health, and health care access and utilization
      4. Develop guidelines/formats for communication with different audiences (Customize findings; use stories)
         1. Explore the use of 30-3-1 practice for disseminating/presenting information to different audiences — 30 page/slide maximum for technical audiences; 3 page/slide maximum for policy audiences, and 1 page/slide maximum for the general population
         2. Determine how best to customize findings to make them meaningful and useable – (why is this important? what does this mean?)
         3. Determine how to create materials that resonate for people with ID/DD (e.g., can they “see themselves” in messaging/imagery?)
         4. Explore best practices for translating information into Easy Read formats, including for those with the most extreme low literacy, by using pictures, video, and screen reader in conversational tone
      5. Review information for potential bias in language. Use stories as well as quantitative data
2. **Optimal use of the data by planning for and conducting a wide variety of analytics:**
   1. Examine data frameworks from other countries or organizations to inform prioritization of data indicators and data gaps
   2. Identify key indicators of health and wellbeing, including on the following:
      1. Public health indicators that are regularly reported markers (e.g., cancer, cardiovascular disease, obesity, mental health, injuries)
      2. Mental health (e.g., depression, anxiety, psychotic disorders, substance use, suicide)
      3. Dental health (e.g., caries, retention of permanent teeth, access to dental care)
      4. Social context (e.g., place of residence, urban/rural, receipt of services and supports)
   3. Establish benchmarks on the indicators to compare with national or other state data on the following indicators:
      1. Health care (preventive, primary, specialist, emergency services, hospitalization)
      2. Behavioral health care
      3. Dental health
      4. Social determinants of health
   4. Enhancing analysis to increase knowledge about people with ID/DD:
      1. Mapping of current/emerging data sources, populations covered (e.g., Medicaid, National Core Indicators for people receiving DD services) and their findings
      2. Analyses disaggregated by key variables to better target problems and interventions
      3. Data analytics to maximize information from existing data (data linking, interoperability, and harmonization of findings)
      4. Need for new data such as long-term studies
3. **Monitoring for new developments and opportunities on health data of people with ID/DD:** 
   1. Transformed Medicaid Statistical Information System (T-MSIS)
   2. Internet panel surveys—
      1. DHHS Office of Assistant Secretary for Planning and Evaluation (ASPE)
      2. Research and Development Survey (RANDS) at National Center for Health Statistics (NCHS) (in collaboration with the census and ASPE~~)~~
      3. National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) grantees
   3. Other data sources, tools, and special studies
      1. National Core Indicators
      2. Special Olympics Healthy Athletes data
      3. Registries
      4. Tools to promote self-report by people with IDD
      5. Tools, datasets and frameworks used in other countries
   4. Data Sets currently used by UCEDDs and other researchers
      1. Behavior Risk Factor Surveillance System (Disability and Health Data System)
      2. National Core Indicators
      3. Electronic Health Records
      4. Medicare and Medicaid claims data
      5. All-payor claims data
      6. National surveillance: National Health Interview Survey, Medical Expenditure Panel Survey, American Community Survey