



**State of the States**  
In Intellectual and Developmental Disabilities

**NACDD/ITACC Executive Director  
Training Session-1**  
Questions and Responses

1. Are there ways we can support the State of States to get better data from our States?
  - First, continue to advocate for the State DD Agencies engagement in the State of the States PNS data collection and reporting project. Sharing how you use the data ensures that we will have your state represented in the nation's data.
  - Second, as you advocate for system capacity, get involved in data infrastructure development. Be at the discussion when states are building their data infrastructures and identifying data collection methods and variables. This helps to ensure that data about people with I/DD is collected and can be reported.
  - Finally, advocate in your state for data sharing agreements where MCO's and other providers acknowledge data access and support the data collection and reporting to the State of the States .
2. What are all the secondary sources used specific to states?
  - New data sources are being identified all the time as they are developed or as historically used sources are discontinued. An example is the CASPER database that used to be called OSCAR which reports nursing home residents.
  - Additional secondary sources may be identified when the State of the States performs special analyses for states examining specific trends overtime such as state demography, labor market trends, and legislative priorities.
3. From the map presented, is it correct that Puerto Rico and territories are not included?
  - The lack of data access in the U.S. Territories that aligns with longitudinal State of the States budgetary and programmatic variables (such as HCBS and Medicaid expenditures) prevents consistent involvement of the Territories in national data collection. The State of the States has been involved in a series of different conversations with The U.S. Territories over time to support the evolution of data infrastructures to increase future engagement.



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4. Are the Data Ambassadors housed within the state/territory UCEDD?
  - Yes.
5. Do you provide data on the professional turnover taking place across the disability field? This data would be useful to NACDD.
  - The State of the States does not collect this data.
6. What should we do if a state reported numbers to you that don't match what the DD agency shares in other reports? What if they don't report at all?
  - Recognizing the data cycle to understand when the data is collected, and seeing if there is updated data. Understanding the operational definitions for your state to see how they report it to us. If you have further questions reach out to the State of the States team to further explore data discrepancies.
7. Does your data collect people in sheltered workshops by state?
  - Yes.
8. I would like to better understand what counts as I/DD spending.
  - This information can be explored by reviewing our Data Dictionary. [Data Dictionary | State of the States in Intellectual and Developmental Disabilities \(ku.edu\)](#)
9. How many HCBS waivers exist in each state for I/DD? How many states have 1915i?
  - This data can be explored through the CMS Waiver database [State Waivers List | Medicaid](#)
10. How many people are sitting on waiting lists in each state?
  - This data is not collected in the State of the States