March 2023
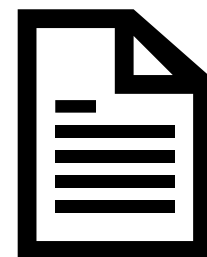# Data Coordinator's Quarterly Call

March 1, 2023

- Update for UCEDDs with No-Cost Extensions(NCE) (UCEDDs-Only)
- Update on the Proposed UCEDD Performance Measure on Equity, Diversity, and Inclusion (ED&I)
- Upcoming Resources
- NIRS Boot Camp
- Demonstration of NIRS Modifications (All Centers/Programs)
- Updates in the Autism CARES Module for PY2022/FY2023 (LENDs and DBPs-only)
- Roundtables (All Centers/Programs)

Update for UCEDDs with No-Cost Extensions (NCE)

- Complete data entry by **October 1st, 2023.**
- To include Projects, Activities, and Product records in your No-Cost Extension:
  - Use the custom field at the bottom of the form: "Include record in No-Cost Extension (NCE) For:"
  - Be sure to select the correct year, "FY2022 (July 1, 2021 – June 30, 2022)"
  - All Centers with NCEs (17) in FY22 will see this field at the bottom of the page in NIRS.
- If your Center received a NCE in FY22, but the field is missing in the projects, activities, or products dataset, please contact NIRS@aucd.org.

| Include record in No-Cost Extension (NCE) for | FY2022 (July 1, 2021 - June 30, 2022) | ⌄ |

Save Cancel

UCEDD Supplemental Reporting

- UCEDD Supplemental Funds
  - [Expand COVID-19 Vaccine Access](#) (CDC funding)
  - Please send submissions using the linked data collection tool to URC@aucd.org by **Friday, March 31, 2023.**

- Public Health Workforce (American Rescue Plan funding)
  - Official guidance is in UCEDD Annual PPR Part 5 for 2023 and 2024 only
  - Due date: July 30, 2023 (interim report in Part 5) and July 30, 2024 (in the final report in Part 5)
  - Completed in NIRS

  OIDD Program Performance Report, Part 5: Expanding the Public Health Workforce within the Disability Network Program Measures

Update on the proposed UCEDD Performance measure on Equity, Diversity, and Inclusion (ED&I)

Ashley Jacinth Ogbonna-Salmon
March 1, 2023

A Systems Change Perspective

1. Investments into the development of equity metrics across our institutions seems to have resulted from the increased awareness of health disparities

2. Recent events have tested our institutions' capacity to be culturally responsive

3. The desire for sustainable change and the lack of measurable impact has fueled an interesting phenomenon where measurement gaps are identified and often inadequately filled

Equity　　　**Diversity**　　　**Inclusion**

- <u>Audience</u>: Anyone in the network, particularly those with access to underrepresented communities

- <u>Goal</u>: To understand how UCEDDs may already be assessing progress of *Equity, Diversity, Inclusion* initiatives

- <u>Method</u>: Semi-structured interviews and *Grounded Theory* qualitative analysis

- <u>Results</u>: In our grounded research, we found that recent UCEDD Network activity led to our research participants' investments in measuring key network concepts: *equity, diversity, inclusion*. Some participants encountered more structural barriers than others at the UCEDD that minimized their capacity to measure these complex ideas.

Serving the Whole Person

Systems Change Framework

Seeing a system:
What are the elements of a system?

Institutional Structures that *shape* **Pathways** which affect **Individual Outcomes**

- Incentives
- Constraints
- Opportunities

- Capacity
- Connections

Seeing systems change:
How can initiatives build systems that work better for individuals?

What keeps systems from working well for individuals?

Structural Barriers that *restrict* ability of actors to improve **Ineffective Pathways** which lead to **Limited Individual Outcomes**

- Adverse Incentives
- Undesirable Constraints
- Limited Opportunities

- Insufficient Capacity
- Missing Connections

How do systems change initiatives contribute to systems change results?

Effective Collaboration supports **Effective Systems Change Initiatives** contributing to **Conducive Structures** that *enable* actors to build **Improved Pathways** which lead to **Improved Individual Outcomes**

- Strong Member Engagement
- Hierarchically Unified Structure & Formalized Process
- Effective Accountability Framework

- Altered Incentives
- Relaxed Constraints
- New Opportunities

- Increased Capacity
- Improved Connections

Implications of Exploratory Phase

1. Idea of data health/quality, or more specifically, ***Data Reliability**** emerged as it relates to collecting data _at the UCEDD_ for multiple purposes (i.e., evaluation, collective impact, data dissemination, reporting back to funders, etc.).

   Structural Barriers

2. Idea of ***Data Literacy**** emerged as it relates to collecting data _on and with_ people with disabilities, including ID/DD, from historically underrepresented communities.

   Pathways

3. _Data Reliability/Literacy_ implicates **NIRS** and the need for continued support from **Data Coordinators, Directors & Program Staff** throughout the network.

   Collaborate

4. The scope of the project implicates **people with disabilities** (PWD), more specifically, people with ID/DD as key stakeholders; should be included in all phases of the project.
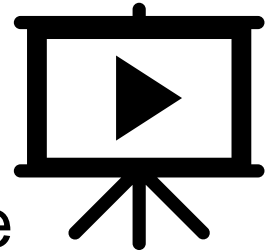
   Individual Outcomes

*Data Reliability: data is complete and accurate (Talend, 2023)
*Data Literacy: the ability to explore, understand, and communicate with data (Tableau e-learning, 2023)

- LEND Program Quality Improvement (LPQI) video tutorials in progress
  - More information will be shared as they are available

- NIRS Calendar for 2023 is in progress
  - More information will be shared as they are available

- [2023 Spanish Paper forms](#) have arrived!
  - Data entry into NIRS must be in English

- The [NIRS Boot Camp for MCHB Training Programs](#) has been archived
  - Materials for each session are linked at the top of the page

Trainees Dataset

- Gender field (new list)
  - Long/Medium & Short-Term trainee forms
  - Faculty/Staff profile form (coming up by the end of Feb)
  - All Reports/ Custom Reports/ AUCD Import
  - DGIS Export
- Race (display order)
- Long-Term Trainee Survey Modifications (UCEDD/LEND, LEND, DBP, LEAH, PPC)
  - For-Profit + Non-profit + Hospital to = Clinical health care setting (includes hospitals, health centers, and clinics)
  - Update "Working with underserved populations or vulnerable groups" to "Working with populations that are underserved or have been marginalized"

Trainee Surveys

*5. Does your current work relate to populations that are underserved or have been marginalized? (i.e, Immigrant Populations Tribal Populations, Migrant Populations, Uninsured Populations, Individuals Who Have Experienced Family Violence, Homeless, Foster Care, HIV/AIDS, people with disabilities, etc)

○ Yes   ○ No

*6. Select primary type/setting of employment: (If you work in a UCEDD, LEND, LEAH, PPC, or DBP, it is likely that you work in a postsecondary or clinical health care setting. Please select the most appropriate option.)

○ **Student**

○ **Schools or school system (includes early intervention programs, elementary, and secondary)**

○ **Post-Secondary Setting**

○ **Government agency**

○ **Clinical health care setting (includes hospitals, health centers, and clinics)**

○ **Private sector**

○ **Other**

Products Dataset Modifications

- Material Type "Web-based products" > Media type field
  - Social Networking Sites → Social Networking/ Social Media Sites

- Material Type "Peer-reviewed publications in scholarly journals Published/In Press" > Dissemination Vehicle field
  - Social Networking Sites/ Social Media → Social Networking/ Social Media Sites

- Material Type "Distance Learning Modules" > Media type field
  - Wikis (new)
  - Social Networking Sites/ Social Media → Social Networking/ Social Media Sites

A new paragraph will be added to the introduction text at the top of the Autism CARES Module in NIRS:

All questions ask you to report for the grant year ending in **2021 (July 1, 2020-June 30, 2021)**.

Some questions ask you to report on long, medium and short term trainees.

Long Term Trainees are those with 300 or more contact hours with the training program, benefiting from the training grant (both supported and non-supported trainees).

Medium Term Trainees are trainees with 40-299 contact hours in the current reporting year.

Short-term Trainees are trainees with less than 40 contact hours in the current reporting year. Continuing education participants are not counted in this category.

All questions ask you to report for the FY2021 grant period.

All results will be aggregated across grant programs and no comparisons across programs will be made.

Overview of CARES Module and Data Definitions

[Save] [Clear]

Topic Area I: Training Trainees
For help answering Questions in this section, to see your short/medium/long term trainees
click here for Short-term trainees | click here for Medium-term trainees | click here for Long-term trainees
  1. Total number of trainees:
      Short term:

"Some terminology in the CARES Module and Data Dictionary has been slightly updated by ITAC to reduce ableist language (e.g., AS/DD will replace ASD/DD to remove the abbreviation for the disorder). The data collected and reported by programs remains unchanged, and the definitions remain unchanged."

Updates in the Autism CARES Module

Topic Area I: Training Trainees
For help answering Questions in this section, to see your short/medium/long term trainees
click here for Short-term trainees | click here for Medium-term trainees | click here for Long-term trainees

1. Total number of trainees:

In the CARES module, question #1 will no longer be answered by LEND/DBP programs because this data is already provided to MCHB via EHB in your annual performance reports. The question (# of short/medium/long term trainees) will be grayed out in the CARES module so that no responses can be entered by programs.

Short term: �▬

Medium term: ▬▬▬

Long term: ▬▬▬

2. Number of LEND trainees who completed coursework covering one or more of the following topics: early signs of ASD/DD; screening, diagnosis, and/or evidence-based interventions for ASD/DD:
   Medium term:

   Long term:

3. Number of LEND trainees who participated in clinical activities or field work that included one or more of the following topics: early signs of ASD/DD; screening; diagnosis; and/or evidence-based interventions for ASD/DD:
   Medium term:

- Data Entry
  - Data Collection for changes in the gender field

- Feedback on NIRS resources
  - NIRS Calendar Format

- Processes for data cleaning and data quality

Questions?

Survey:
https://www.surveymonkey.com/r/Data-Coordinator-Quarterly-Call-March-2023

Contact nirs@aucd.org with any questions.

Thank you!