

Swimming Upstream Together: How UCEDDs are Partnering with State Leaders Using the NCI to Create Systems Change

AUCD 2017



Michigan Developmental Disabilities Institute

NASDDDS



What is NCI?



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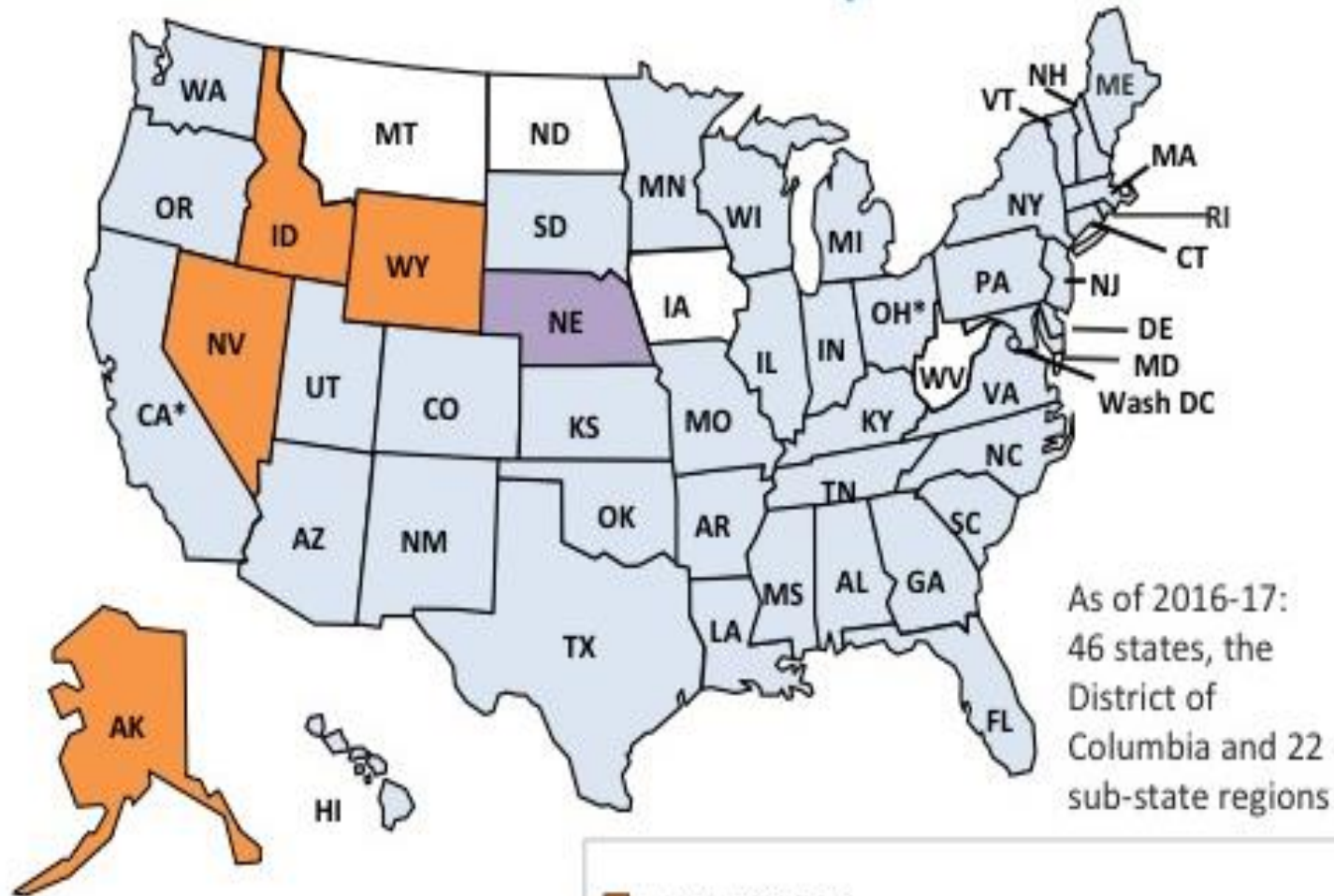
- ❑ NCI is a voluntary effort by public developmental disabilities agencies to measure and track their own performance.
- ❑ 20th year of survey in 2017
- ❑ Indicators address key areas of concern including employment, rights, service planning, community inclusion, choice, and health and safety.

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Human Services
Research Institute

NCI State Participation



■ New in 2015-16
■ New in 2016-17
CA* - Includes 21 Regional Centers
OH* - Also includes the Mid-East Ohio Regional Council



Audrey Rossi

Delaware's University Center for Excellence in
Developmental Disabilities

Delaware's NCI



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- Delaware participates in the Adult Consumer Survey, the Adult Family Survey and the Family/Guardian Survey
 - 2013-2014: State agency administered family surveys, CDS administered Adult Consumer Survey
 - 2014-2015: CDS became responsible for administration of all three surveys

State Agency Partnership



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- Partnership has built since 2013
 - Increased communication and collaboration
 - Key to NCI success
- Dissemination of data with focus on stakeholder input
 - Infographic fliers
 - Focus groups
 - Presentations



**Michigan Developmental
Disabilities Institute**

June Malachowski

Wayne State University,
Developmental Disabilities Institute

Michigan's NCI



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- UCEDD and LEND
- NCI since 2012
 - Partnership with the Michigan Department of Health and Human Services (MDHHS)
- 2012-2016: Adult Consumer Survey – MI-DDI responsible for the administration of the survey and data entry
- Infographic fliers: 2015 & 2016 ACS data – survey participants, state, stakeholders, conferences, etc.



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MDHHS Uses of NCI Data



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 Strategic Planning



 Legislative Reports



 System Level Data Review



 Quality Improvement Initiatives



 Shape and reform the direction of employment



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Michigan's NCI 2015-2016

- 38,000 adults with intellectual and/or developmental disabilities receive services from the Michigan Department of Health and Human Services (MDHHS).
- 435 Individuals were randomly selected and completed the NCI Adult Consumer Survey (*now called the Adult In-Person Survey*)

Michigan: NCI Employment Data 2015-16 Adult Consumer Survey

- 42% Would like a job in the community
- 26% Have employment as a goal in service plan
- 17% Have a paid job in the community
- 59% of those that have a paid job in the community are in a group job with or without publicly funded supports

Using NCI to Address Employment

- Individual competitive integrated employment
- Distinguishing pathways from skill building and small group integrated employment
- Establishing an outcome for the service(s)
- Restructuring the community's understanding of employment and service definitions



UNMCSM

MUNROE-MEYER INSTITUTE

Rachel Ray

Munroe-Meyer Institute,
University of Nebraska Medical Center

Nebraska's NCI



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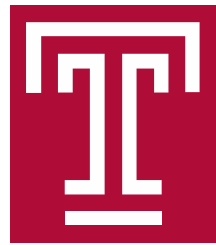
- Nebraska participates in the Adult Consumer In-Person Survey and the Staff Stability Survey
 - 1997: Nebraska was one of the seven states to pilot test the Adult Consumer Survey
 - 2016-2017: Nebraska resumed the administration of the Adult Consumer Survey and the Staff Stability Survey
 - 2017-2018: We are entering our second year and considering administering the Adult Family and the Family/Guardian Surveys

Using NCI data to Track Impact \$1.4m Budget Cut



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- In March, 2017, the DD state budget was cut by \$1.4m; cuts to Medicaid programs totaled over \$3m, and VR cuts totaled over \$1.5m
 - Several rural providers and smaller agencies are scheduled to close due to the cuts.
 - We are using the survey to track changes in:
 - Community Inclusion
 - Employment
 - Transportation
 - Choice and Decision Making
 - Service Coordination



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Institute on Disabilities

Celia S. Feinstein

Pennsylvania's University Center for Excellence
in Developmental Disabilities
Education, Research and Service

Pennsylvania's NCI



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- Involved since NCI's inception in 1997 (member of technical advisory team that wrote the survey)
- Interview more than 5,000 individuals each year
- Add questions that measure outcomes in state's Everyday Lives standards
- State collects both family surveys and Staff Stability Survey (voluntary)
- Use NCI for quality improvement at the individual level

Using NCI to Track Deinstitutionalization



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- Using the NCI to assess institutional closure (Hamburg center)
- Measure progress and outcomes of Benjamin lawsuit
- Collecting data pre and post deinstitutionalization and then again one more time post deinstitutionalization



Partnership for People
with Disabilities

Linking people. Changing lives.

Parthy Dinora

Virginia's University Center for Excellence in
Developmental Disabilities,
Virginia Commonwealth University

Virginia's NCI



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- ❑ Population (N=800, HCBS)
- ❑ We do statewide reporting in addition to the HSRI report—mainly infographics
- ❑ Virginia is in a settlement agreement with the US DOJ—major system transformations are underway

Pilot Project: NCI and Medicaid Expenditure



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- ❑ Involved in a special project linking NCI, Support Intensity Scale and Medicaid claims data to look at the predictors of enhanced outcomes for people who use IDD services (individual and service characteristics)
- ❑ Secured consent to link data and then strip out identifiers
- ❑ Interesting useful findings for the state!!

Human Development Institute

Laura Butler
Claudia Johnson

Human Development Institute,
University of Kentucky



Quality Improvement Committee



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□ **Committee Members:**

- Self-Advocates
- Family members
- HDI NCI staff
- HDI researchers and staff
- State DD Agency staff

□ **Recommendation Areas:**

- Medication Usage



- Relationships



- Health & Wellness



- Employment





□ Recommendations:

□ Previous recommendation example:

- Increase overall percentage of SCL recipients with jobs in the community to at least the national NCI average.

□ Current recommendation example:

- Ensure that if a person expresses an interest in employment that such interest is reflected in the Person Centered Service Plan. Reasons for the absence of employment in the Service Plan should be documented as well as perceived barriers to the person pursuing employment.

Collaboration Success in KY



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KY Division of Developmental and Intellectual Disabilities has contracted with UK-HDI since the start of NCI in KY 1998.

This collaboration has allowed the Division to incorporate projects into our contract with HDI that further the quality of supports for people with DD.

Collaboration



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- In 2014 based on the recommendation of the NCI Quality committee, the Division was able to hire a full time Health and Wellness Coordinator.
- The Coordinator has been instrumental in implementing health initiatives across the state.
- This has resulted in a better educated provider community, and
- Improved health outcomes.

Collaboration



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- In 2016 in collaboration with UK-HDI the Division applied for and was awarded a CDC grant to improve health of people with cognitive and mobility limitations— CHEER Community Health Education and Exercise Resources.
- We are in our 2nd year of a 5 year grant.

Ongoing Collaboration



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- A representative of HDI is a member of the KY Commission for Services and Supports for People with Intellectual and Other Developmental Disabilities, which advises the Department on DD issues.
- Once a year HDI presents to the Commission on the needs survey done by the 3 DD sister agencies. These are used to drive the work of the Commission's three committees, and to drive changes to DD waiver programs.

QUESTIONS AND DISCUSSION

