



NASDDDS & HSRI

NCI Research and Analysis: Accomplishments and Future Plans

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Human Services
Research Institute

NASDDDS

National Association of State Directors of Developmental Disabilities Services

NCI Research Opportunities



- To exploit the biggest data base in the world on the characteristics and outcomes of individuals receiving ID/DD services and support (approx. 18,000 in 14-15)
- To highlight trends in the field (e.g., where do people live, how many are employed)
- To identify issues and challenges (e.g., use of psychotropic medications; aging caregivers)
- To fill knowledge gaps (e.g., characteristics and outcomes of individuals with ASD and their families)
- To provide data to researchers for further analysis and publication (e.g., ICI, UMN, U of IL) knowledge base
- To make data accessible to policy-makers and program managers



Vehicles for Dissemination of Research Findings

- Data Briefs
- Sarah Taub Webinar Series
- Conference Presentations
- Publications in Peer Reviewed Journals
- Collaboration with Research Partners
- Citations in other works (e.g., UCP, Emerson, et al., NBC, etc.)




Recent Data Brief Findings



- People who have guardians make fewer choices including who they live with and what they do with their time (*What NCI Data Reveal About Service Delivery and the Respect Given to the Rights of People With I/DD, 2015*)
- People who need behavior support are more likely to say they are scared at home, at their day program, or in their neighborhood and are less likely to feel that they have enough privacy at home (*What Do NCI Data Reveal About Individuals With ID/DD Who Need Behavior Support? 2014*)



Exercising Choice

 NATIONAL CORE INDICATORS™	No guardianship	Limited guardianship	Full guardianship
Choice – Made decision or had some input into decision			
Home	62%	46%	41%
Roommates	54%	42%	35%
Staff (day & residential)	69%	64%	60%
Daily schedule	90%	79%	77%
What to buy	93%	83%	81%

Recent Findings

- Respondents who communicate nonverbally were less likely to participate in activities in the community (*What Do NCI Data Reveal About Individuals With Intellectual and Developmental Disabilities Who Communicate Nonverbally? 2014*)
- People working in individual jobs average less than 14 hours per week, and many more individuals want jobs than have employment as a goal in their plan (*Working in the Community: the Status and Outcomes of People with Intellectual and Developmental Disabilities in Integrated Employment – an Update, 2014*)



Future Data Briefs

- The Influence of Friendship on Selected Outcomes Including Health, Inclusion and Employment
- The Characteristics and Outcomes of Individuals Who Are Self-Directing
- <http://www.nationalcoreindicators.org/resources/data-briefs/>



Sarah Taub NCI Webinar Series



- Rights and Respect (including Supported Decision-Making, recorded)
- What Do NCI Data Reveal About Individuals With Intellectual and Developmental Disabilities Who Need Behavior Support?
- Understanding NCI Reports
- Individuals with ID/DD Who Communicate Nonverbally
- How Do Services for People with Intellectual and Developmental Disabilities Compare By Race/Ethnicity
- September 10, 2015: Self-Determination: Are We there Yet? A Brief Status Report from the US and Beyond

(email dhiersteiner@hsri.org for info;

<http://www.nationalcoreindicators.org/resources/presentations/>



Conference Presentations



- AAIDD, June, 2015:
 - Systems Change to Promote Rights: A Supported Decision Making Initiative and National Core Indicators Data
 - Friendship Matters! Improving Health and Well-Being by Supporting Relationships
 - New Federal HCBS Expectations: HCBS Setting Transition Plans & Data for Tracking Systemic Compliance
 - The National Core Indicators Staff Stability Survey



Conference Presentations

- National Goals Conference, Aug 6-7, 2015
 - NCI Data Trends and Research
- HCBS Conference, Aug/Sep 2015
 - Do race and ethnicity play a role in health care access and outcomes?: National Core Indicators analyses
 - National Core Indicators' Staff Stability Survey: Investigating DSP workforce stability and quality



Upcoming Conferences

- Claiming Full Citizenship: Vancouver, CANADA in Nov., 2015
 - Measuring the Impact of Self-Direction at the State and National Level
- APHA Conference: Chicago, IL in Nov., 2015
 - Exploring Health Disparities Among People with Intellectual and Developmental Disabilities
 - What Are the Issues and Do Race and Ethnicity Play a Role?



Peer Reviewed Journal Articles

- ‘Race/Ethnicity and the Use of Preventive Health Care Among Adults with Intellectual and Developmental Disabilities’
 - *Medical Care*, October, 2014
- ‘National Core Indicators©: Data on the current state of employment of adults with IDD and suggestions for policy development’
 - *Journal of Vocational Rehabilitation*, February, 2015



Publications

- Chapter in Schalock and Keith, *Cross Cultural Quality* in press
 - A Focus on System-Level Outcome Indicators
- Current project:
 - What NCI data show about adults with Autism Spectrum Disorder



Publications Using NCI Data

- ‘National health surveillance of adults with disabilities, adults with intellectual and developmental disabilities, and adults with no disabilities.’
 - Susan Havercamp and Haleigh Scott. *Disability Health Journal*, 2015
- ‘Impact of adulthood stage and social-environmental context on body mass index and physical activity of individuals with intellectual disability’
 - Tamar Heller, Kelly Hsieh, Julie Bershadsky, Sarah Taub. *Intellectual and Developmental Disabilities*, 2015



Use of the Dataset by Other Researchers – Requirements

- The research is consistent with NASDDDS and HSRI mission and guiding principles.
- The researcher must destroy or return the data sets when the project is complete.
- The researcher must establish a plan to keep the NCI team up to date on the progress of the research, including any changes to the **Research Proposal**. The plan should also detail expectations for the destruction or retention (with permission) of NCI data used for this research.
- The researcher agrees to share the findings of the research (including the final research report) with the NCI Project Team, *prior to final publication or distribution*.
- Specific states will not be identified in the reporting of data unless prior approval has been received by the researchers from the relevant state(s).
- The researchers agree to cover the cost of the established user fee.



How to Request Dataset for Research Purposes

- Contact Dorothy (dhiersteiner@hsri.org) for more info on acquiring NCI datasets for research purposes.

