Data Opportunities to Advance Dementia Home- and Community-Based Services (HCBS) Through Direct Care Workforce Measurement and Analysis

Please Note: The presentation portion of this webinar will be recorded. ***The Q&A session will not be recorded***

CaN-D
Community Care Network for Dementia

The **Community Care Network for Dementia** (**CaN-D**) is comprised of over 390 researchers, providers, and policymakers seeking to advance Medicaid home- and community-based services (HCBS) research and practice for persons living with dementia.

What Is Our Goal?

CaN-D seeks to:

- foster knowledge sharing to advance innovative dementia HCBS research
- generate data tools on structure, process, and outcome measures of dementia HCBS
- grow the bench of dementia HCBS researchers
- facilitate translation of research into dementia HCBS policy changes

What Are Our Network Activities?

- Quarterly network meetings
- Monthly working group meetings
- Annual intensive data workshops
- Research translation and dissemination training seminars
- Dementia HCBS Data Hub

CaN-D
Community Care Network for Dementia

Meet the CaN-D Team

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CaN-D
Community Care
Network for Dementia

If you are interested in joining the CaN-D network, please scan the QR code below:

Sign up to receive our newsletter, network updates, and opportunities to connect with other CaN-D members!

AWARD Network

Advancing Workforce Analysis and Research for Dementia

SAVE THE DATE:

Annual Meeting:

Gerontological Society of America

November 4, 2026

Sign up and provide ideas for future webinars:

AWARD Network

Advancing Workforce Analysis and Research for Dementia

Grant Writing Groups!

The AWARD Network is organizing grant writing groups for grants to be submitted late winter. These will be groups of 3-5 people and will provide an intensive, supportive period for preparing proposals to NIH or similar proposals to other funders.

The peer-supported groups will run for about 3-4 months before the submission deadline.

Participants should expect to commit 6 hours of time per week. Two hours will be for synchronous group feedback sessions. Four hours will be for writing, which can be done in two 2-hour synchronous sessions or on your own time.

If you are interested in joining a group, please sign up using the Qualtrics form from the 8/24 email. The deadline to sign up is Saturday, September 11.

AWARD Network

Advancing Workforce Analysis and Research for Dementia

Other Updates:

GSA abstract acceptances?

Anybody attending any other conferences?

Interested in presenting in 2027?

Let us know!

Sign up and provide ideas for future webinars:

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Funding Acknowledgement

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CaN-D Community Care Network for Dementia

AWARD Network

Today's Webinar

Data Opportunities to Advance Dementia Home- and Community-Based Services (HCBS) Through Direct Care Workforce Measurement and Analysis

Our Speakers

Rosa Plasencia, JD

Senior Director, National Core Indicators – Aging and Disabilities, ADvancing States

James Wagner, PhD

Research Professor, Survey Research Center, Institute for Social Research, University of Michigan; National Dementia Workforce Study, Data Collection Core Lead

NATIONAL CORE INDICATORS-AGING AND DISABILITIES (NCI-AD™)

NCI STATE OF THE WORKFORCE SURVEY, AGING AND DISABILITIES

Rosa Plasencia
Dorothy Hiersteiner

NCI
NATIONAL CORE INDICATORS
PEOPLE DRIVEN DATA

Agenda

- What is National Core Indicators®?
- What is NCI-AD™?
- What is the State of the Workforce-AD?
- How to get involved

National Core Indicators (NCI)

NCI tools collect data on performance and quality of life indicators directly from:

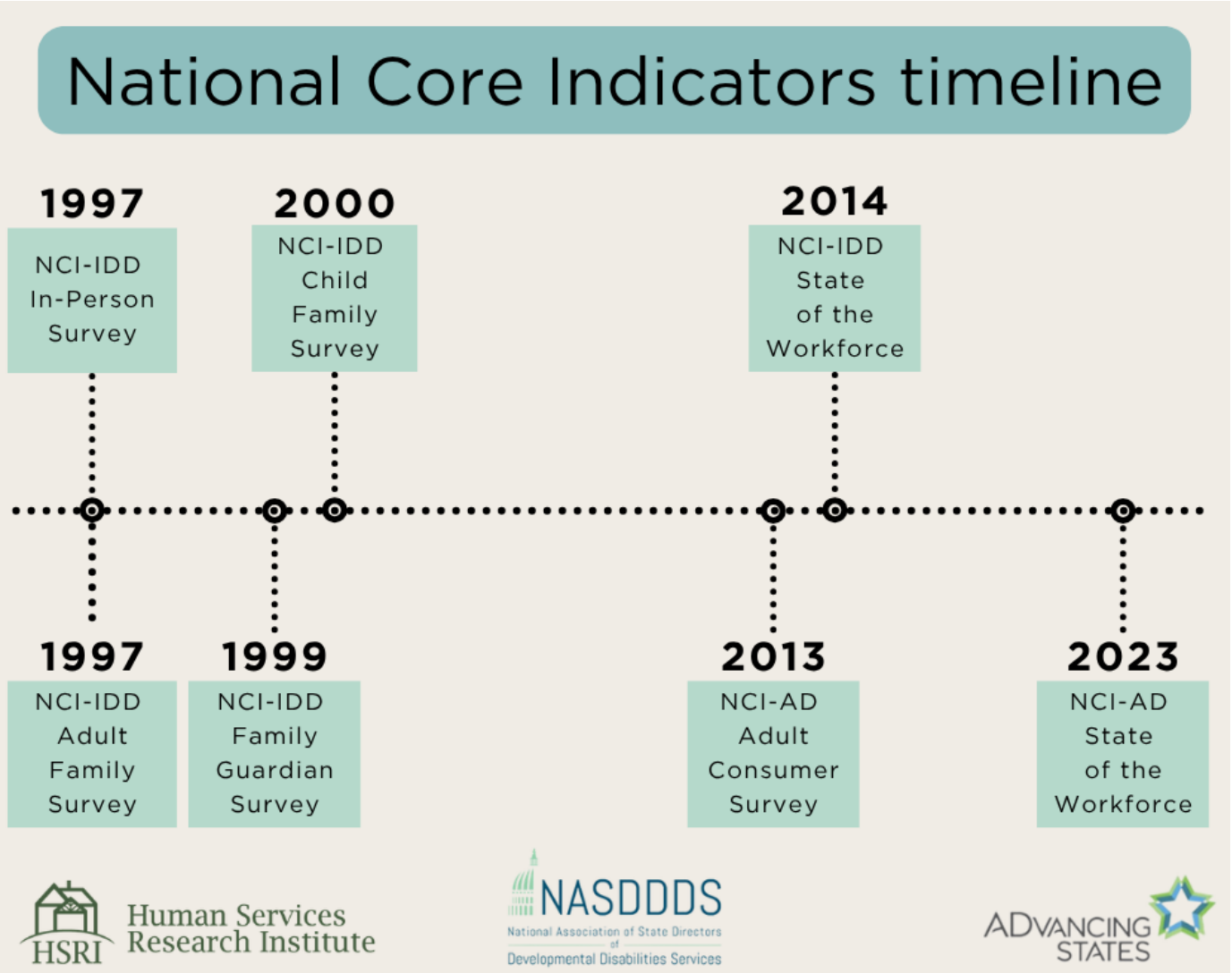
(1) people who use disability and/or aging services systems;

(2) families; and

(3) those who deliver services

Participating states:

- NCI-IDD IPS and Family Surveys: 48
- NCI-AD: 26
- State of the Workforce: 30 states for the NCI-IDD SoTW, and 6 states for NCI-AD SoTW



Goals of NCI

Establish a **nationally recognized set of performance and outcome indicators** for aging & disability (including IDD) service systems

Use **valid and reliable** data collection methods & statistical techniques to capture information directly for people who use services

Report individual state results and **national benchmarks** of indicators of system-level performance

Why are Data Needed:

State government is in position to use data to make **data-driven policy decisions that impact providers, DSWs and people receiving supports**.

Provider agencies can use the data to **determine where recruitment and retention efforts can be targeted and understand how they compare to providers in their state and nationally.**

What data are needed?

- **Describe the workforce:**
  - Demographics
  - Types of services provided
- **Outcomes we're seeing**
  - Turnover
  - Tenure (length of employment)
- **What's contributing to those outcomes?**
  - Wages
  - Benefits
  - Recruitment and retention strategies

NCI State of the Workforce - Aging and Disabilities

Conducted by states, HSRI and ADvancing States to gather information about the strengths, weaknesses, and trends of the direct care workforce

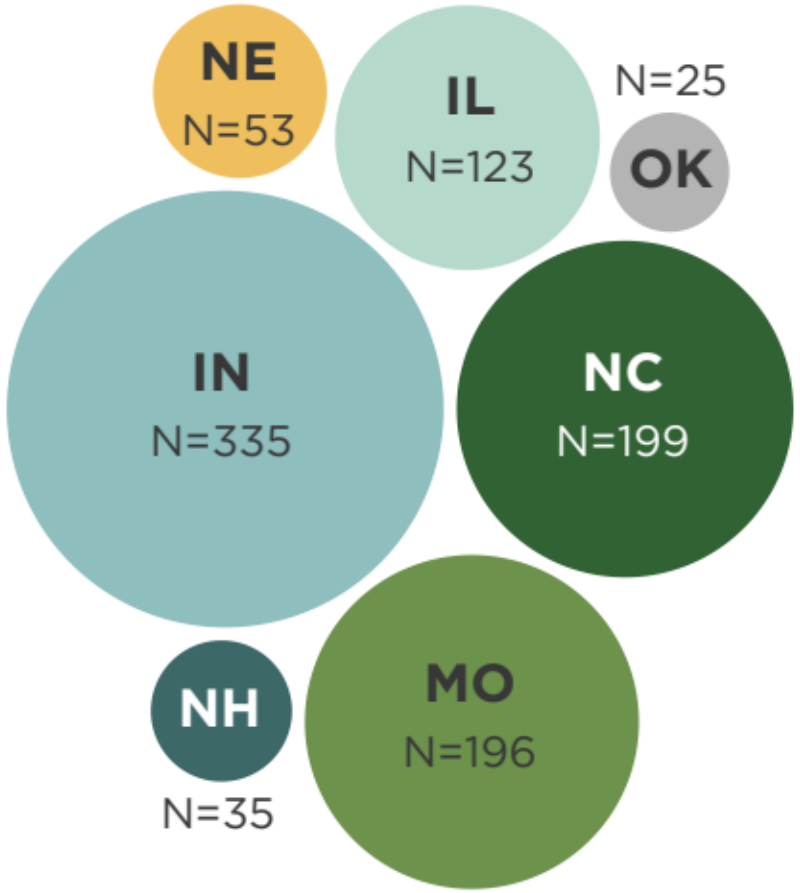
NCI State of the Workforce, AD in 2024

7 states participated

- **966 provider agencies**

This is the last year of NCI-AD State of the Workforce.
The Cross Population Survey will be rolled out in Feb 2027.

State of the Workforce AD in 2024



More than 100,631 direct support workers with 966 provider agencies in 7 states participated

- Data refers to period between Jan 1, 2024-Dec 31, 2024
- Most states administer the survey to all agencies who provide direct support to older adults and/or people with physical disabilities

What is the “The AD population?”

“The AD population:” older adults and/or individuals with physical disabilities who access publicly funded services in:

- Medicaid waiver programs
- Medicaid state plan programs, and/or
- State-funded programs, and/or

Older adults served by Older Americans Act programs.

Cannot drill down to dementia-specific services

What kind of workers are we talking about?

Direct Service Workers (DSWs) are on an agency's payroll and:

- Support people to maintain independence
- Provide personal assistance such as support to get out of bed, bathe, dress and groom
- Conduct basic clinical tasks such as monitoring vital signs, helping with prescribed exercises or administering medications
- Assist with housekeeping, grocery shopping and cooking, accompany clients to doctor appointments or other errands
- Provide companionship
- Provide support in community engagement activities
- Provide support in day centers or other day activities
- Provide respite support

Who is not included in the survey?

The following are excluded from this survey:

- Nursing Home Facilities
- Self-directed DSWs—this includes many family caregivers
- Clinically licensed staff
  - CNAs may be included if they only conduct basic clinical tasks such as monitoring vital signs, helping with prescribed exercises or administering medications

Survey Implementation

States identify eligible provider agencies

States work with Provider Networks and other interested parties to raise awareness of the survey and ensure buy-in

Service providers enter data into online database collection system

States use different mechanisms to ensure robust response

- Participation is written into statute
- Incentives
- Written into contracts
- No more referrals!

SELECTED DATA from 2024

	Valid responses	Total pop	Response rate	Margin of error
ILLINOIS	123	255	48.2%	6.37%
INDIANA	335	1134	29.5%	4.50%
MISSOURI	196	827	23.7%	6.12%
NEBRASKA	53	133	39.8%	10.48%
NEW HAMPSHIRE	35	117	29.9%	13.93%
NORTH CAROLINA	199	1449	13.7%	6.45%
OKLAHOMA	25	116	21.6%	17.44%
Total	966	4031	--	--

Percentage of agencies that turned away or stopped accepting new service referrals in 2024 due to DSW staffing issues

	N	2024	2023
ILLINOIS	123	7.3%	16.0%
INDIANA	334	15.0%	27.5%
MISSOURI	195	29.2%	35.9%
NEBRASKA	53	3.8%	
NEW HAMPSHIRE	35	42.9%	
NORTH CAROLINA	199	19.1%	
OKLAHOMA	25	20.0%	
NCI-AD Average	**964**	**17.7%**	28.8%

2024 NCI-IDD Average: 26.6%

Agency type

	Private for-profit agency	Private non-profit agency	State/county government	Other government
ILLINOIS	75.6%	23.6%	2.4%	0.0%
INDIANA	83.4%	9.9%	8.0%	1.0%
MISSOURI	78.1%	14.6%	8.9%	0.0%
NEBRASKA	49.1%	28.3%	15.1%	7.5%
NEW HAMPSHIRE	54.3%	45.7%	0.0%	2.9%
NORTH CAROLINA	87.3%	8.6%	5.1%	0.0%
OKLAHOMA	48.0%	52.0%	0.0%	0.0%
NCI-AD Average	80.3%	13.7%	6.9%	0.7%

NCI-IDD 61.7%

NCI-IDD 34.7%

What is Turnover Ratio?

- A way to demonstrate the **rate at which employees are separating** (leaving) an employer
- Turnover ratio is a **percentage**, so it allows for comparisons between entities.
- A **higher turnover** means that **MORE employees are leaving**

$$\frac{\text{\# of separated DSWs in 2024}}{\text{\# of DSWs on staff as of Dec 31, 2024}}$$

Average turnover ratio

	NCI-AD 2022	NCI-AD 2023	NCI-AD 2024	NCI-IDD 2024
ILLINOIS		36.4%	28.1%	41.3%
INDIANA		44.7%	46.4%	37.5%
MISSOURI	48.2%	46.1%	46.3%	46.5%
NEBRASKA			47.7%	51.3%
NEW HAMPSHIRE			46.0%	
NORTH CAROLINA			51.3%	23.9%
OKLAHOMA			42.9%	39.1%
NCI-AD Average			45.1%	37.1%

What is tenure?

“Tenure” is the length of employment.

State of The Workforce measures tenure of two DSW populations:

- the length of employment of those currently employed
- the length of employment of those who left

Allows you to see where additional support might be needed.

- If a large percentage of employees are leaving after only 6 months employment, an agency might see that new employees need **more training and support** at the start of employment.
- If a large percentage of employees are leaving after 5 years, it can tell you something about **career opportunities or pay parity**

Tenure of DSWs on payroll as of 12/31/24

	Less than 6 months	6-12 months	12-24 months	24-36 months	36+months
ILLINOIS	19.3%	23.3%	17.7%	14.3%	25.4%
INDIANA	19.8%	24.3%	22.8%	13.6%	19.5%
MISSOURI	17.8%	17.4%	17.1%	13.3%	34.5%
NEBRASKA	21.2%	14.4%	16.0%	12.0%	36.5%
NEW HAMPSHIRE	18.4%	18.0%	19.0%	14.0%	30.6%
NORTH CAROLINA	21.6%	16.9%	15.9%	10.7%	34.9%
OKLAHOMA	15.9%	12.8%	19.0%	11.4%	40.9%
NCI-AD Average	19.6%	21.0%	19.6%	13.0%	26.8%

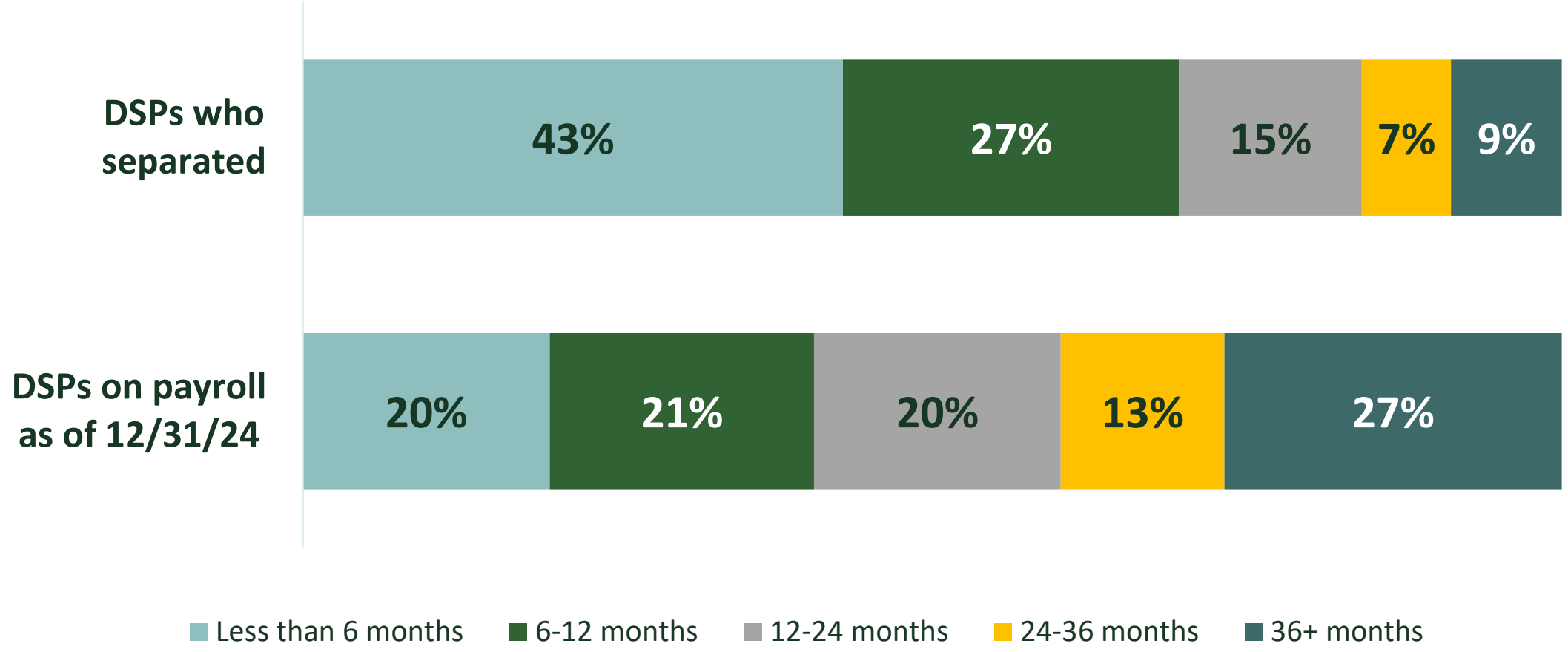
40.6% employed less than a year

Tenure of DSWs who separated in 2024

	Less than 6 months	6-12 months	12-24 months	24-36 months	36+ months	# of agencies w/ data on tenure of separated DSWs
ILLINOIS	34.5%	21.0%	19.3%	9.5%	15.7%	84.3%
INDIANA	42.2%	31.5%	14.3%	6.9%	5.0%	79.1%
MISSOURI	43.2%	23.4%	16.2%	7.0%	10.2%	81.8%
NEBRASKA	39.7%	16.5%	17.7%	6.4%	19.7%	71.2%
NEW HAMPSHIRE	40.7%	29.6%	13.4%	6.6%	9.6%	97.0%
NORTH CAROLINA	50.5%	24.2%	9.3%	6.2%	9.7%	77.3%
OKLAHOMA	46.3%	16.8%	12.6%	8.1%	16.3%	100.0%
NCI-AD Average	42.9%	26.7%	14.5%	7.1%	8.8%	80.1%

In all states, over 50% of those who separated did so within 1 year

Tenure among those who were on payroll as of 12/31/24 (“Stayed”) and those who separated in 2024

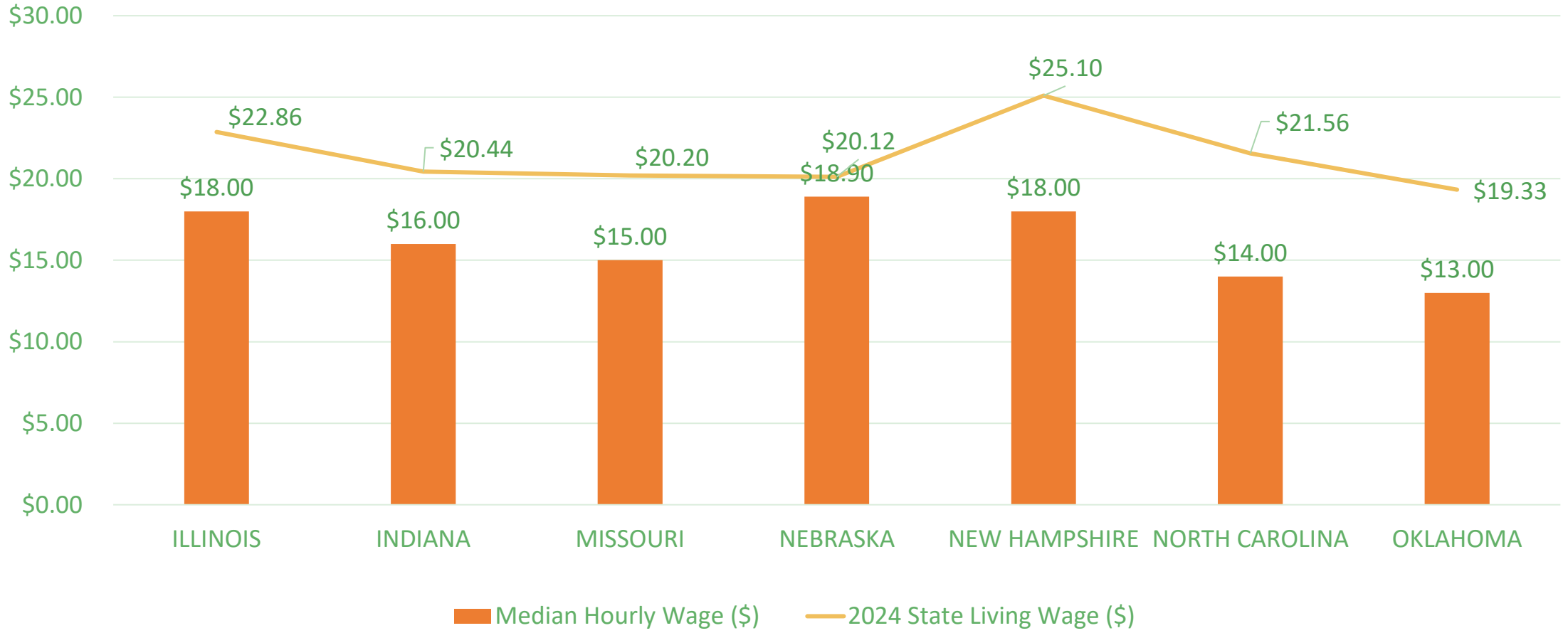


WAGES

	Median hourly wage	Median hourly wage 2023	*IDD median hourly wage*	% w/an average hourly wage more than $0.50 below living wage
ILLINOIS	$18.00	$17.00	*$18.75*	100.0%
INDIANA	$16.00	$15.00	*$16.02*	98.7%
MISSOURI	$15.00	$14.50	*$18.00*	98.4%
NEBRASKA	$18.90		*$18.00*	72.5%
NEW HAMPSHIRE	$18.00			100.0%
NORTH CAROLINA	$14.00		*$15.76*	99.4%
OKLAHOMA	$13.00		*$13.00*	100.0%
NCI-AD Average	$16.00		*$18.39*	98.2%

The living wage shown is the hourly rate that an individual in a household must earn to support themselves and their family. The assumption is the sole provider is working full-time (2080 hours per year). Figures are in dollars ($) and were retrieved from: http://livingwage.mit.edu

Median Hourly Wage for All DSWs and The Statewide Living Wage



Benefits

	Paid time off (NCI-AD)	Paid-time off (NCI-IDD)
ILLINOIS	73.6%	91.9%
INDIANA	37.3%	73.5%
MISSOURI	41.8%	83.5%
NEBRASKA	98.1%	75.3%
NEW HAMPSHIRE	80.0%	
NORTH CAROLINA	59.7%	54.8%
OKLAHOMA	84.0%	75.4%
NCI-AD Average	49.4%	69.8%

Survey also asks about:

- Paid vacation, sick, personal time
- Dental and vision coverage
- Health insurance
- Retirement
- Other benefits like FSA, transportation, childcare, etc.

Ways State systems can use the data:

- **Inform understanding of challenges facing providers and workforce**
- **Target TA to providers**
- **Legislative advocacy**
  - Rates
  - Policy
- **Shared with interested groups:**
  - leadership, disability law center, advocates, family members, and service providers including leadership of the provider association
- **Reporting requirements**
- **Track impact of workforce development policies**

Ways researchers can use the data

- **Researchers can access the data by emailing dhiersteiner@hsri.org**
  - State variable is de-identified in most cases
  - Data use proposal, Data use policy and fees all apply
- **Direct linkages between the NCI-AD ACS and SoTW cannot be made.**
  - Data can be examined at the state level
- **Researchers have used the IDD SoTW data to:**
  - Examine the impact of wage pass through laws on turnover
  - Examine the predictors of turnover
  - Examine differences between small, medium and large provider agencies
  - Examine which “incentives” (benefits, wages, retention strategies) have the most impact on turnover

But wait, there's more….
What is the Cross Population Survey?

NCI developed the NCI State of the Workforce Cross Population Survey, a single tool to be used by providers who support the IDD and/or the AD population. This will replace the NCI State of the Workforce Surveys for IDD and AD.

What will this new survey do:

1) Simplify survey administration and data collection for states with providers that provide supports to various populations
2) Collect data needed for Access Rule Payment Reporting compliance
3) Retain the collection of some data by population to provide data for population specific quality improvement and program- and policy-making

Questions? Comments?

rplasencia@advancingstates.org
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NDWS Home Care Survey: Sampling, Data Collection, Data Release

James Wagner, PhD

Acknowledgement

- This work was supported by a grant from the National Institute on Aging (U54AG084520; MPI: Maust and Spetz)

Family of four surveys

- Community Clinician – physicians, NPs, PAs

- Nursing Home Staff
  + Org-level survey
- Assisted Living Staff
  + Org-level survey
- Home Health/Care Staff
  + Org-level survey

} Nearly identical content, focus for today

Family of four surveys

- Community Clinician – physicians, NPs, PAs

- Nursing Home Staff
  + Org-level survey
- Assisted Living Staff
  + Org-level survey
- Home Health/Care Staff
  + Org-level survey

Nearly identical content, focus for today

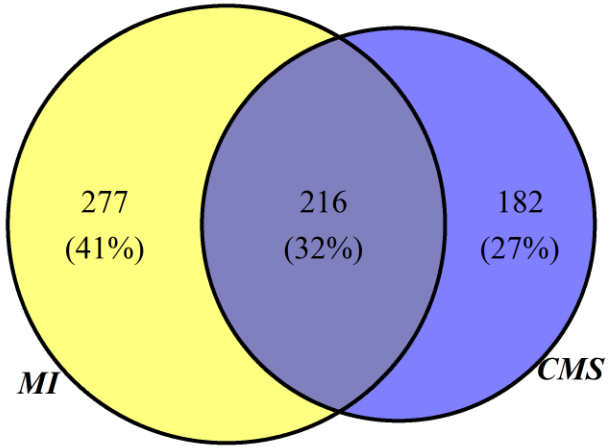
Home Health and Home Care

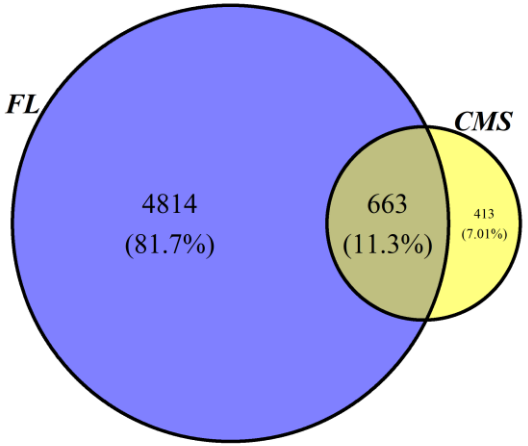
- The challenge: home-delivered care comes from multiple types of agencies, not all of which are licensed by states, plus direct hiring
  - Medicare reimburses only home health agencies (shorter-term care)
  - Medicaid may reimburse personal care, which focuses on support for activities of daily living (ADLs), but state policies differ
  - Some states' Medicaid plans have consumer-directed models of care through which households hire directly

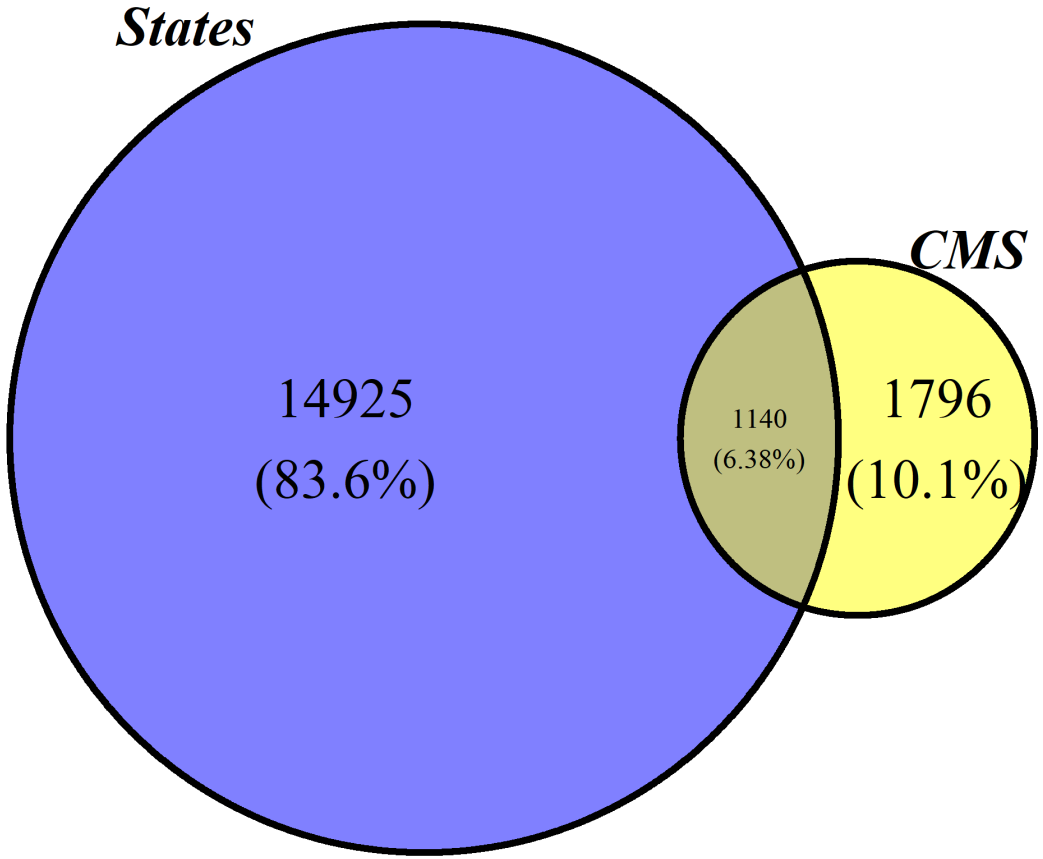
Home Care Frame in Year 1

- CMS-registered home health agencies
- Certified as a Medicare or Medicaid health provider
- Service includes skilled nursing, therapy, and home health aides

Home Health and Home Care







States: FL, IN, LA, MN, NV, NH, OH, VM, VA, WV

Home Care Frame expansion in Year 2

- The CMS-registered agencies are not a complete list of the target population
- Expanding the sample frame
  - Year 2: Used state licensing lists to identify home health and home care agencies
    - PCA training requirements
    - Managed Long-Term Services and Support (MLTSS) programs
- Still likely there is undercoverage of population

HC: Stage 1

- The Home Care surveys start with a **first-stage sample of agencies**
  - Year 1 = 200 agencies
  - Year 2 = 300 agencies
  - Administrators complete a questionnaire about the facility/community/agency
- We ask each establishment to provide a **roster of eligible staff**
  - We provide an **incentive** to the establishment
  - **Experimenting** with incentive structure
    - $1,800 to the establishment, $200 to the administrator
    - $2,000 to the establishment
- Contact
  - Mail, Telephone, Email
- **Nonresponse Follow-up** is by telephone

Stage 2: Eligible staff for rostering

- Recruited agencies provide a roster of staff
- NDWS draws a sample and contacts staff directly
- Staff asked to complete the survey via the web
- Paper-and-pencil version of the survey supplied later in the protocol

Eligible Titles
Registered Nurse
LPN/LVN
CNA
Nurse Aide/Assistant
Home Health Aide / Assistant
Personal Care Aide / Assistant
Activity staff

HC Data Collection

Organization & staff surveys:

- HC organizations
  - Mailed letter
  - $2,000 or $200/$1,800 incentive
  - Telephone follow-up
  - Email, mail follow-up as available

- HC Staff survey
  - Mailed letter
  - $100 incentive
  - Follow-up with mail, telephone, email as available

Organization

- ✓ Pre-field contact tracing
- ✓ Pre-notification letter
- ✓ Telephone
- ✓ Email/Mail to named contacts
- ✓ Mailed nonresponse letter
- ✓ Reminder telephone calls

Staff

- ✓ Email/Mail invitations
- ✓ Email reminder
- ✓ Thank you/reminder postcard
- ✓ Email reminder
- ✓ Mailed PAPI survey
- ✓ Staff NRFU telephone attempts

Home Care Pilot in Year 2

- Some states maintain lists of individual Direct Care Workers for home care
- We identified one state that shares the list
- Added a test of individual Direct Care Workers from this state-level list
  - N=500

Y1 and Y2 Data Collection Results

Survey	Sample size	Completed surveys, n
Year 1		
organization	200	4
staff	90	25
Year 2 Agency		
organization	300	10
staff	259	49
Year 2 DCW		
staff	500	131

Year 3 HC Data Collection

- New sample of agencies (n=1,000)
  - Changed the rostering procedure
  - Ask the administrator to forward the email invitation to all of the eligible staff
  - Staff can take a screening survey
    - Determines eligibility
    - Allows us to control ineligibles, multiple survey completions per person, bots, etc.
  - NDWS samples eligible staff who have completed the screening survey
    - Conditional RR determined as completes/reported staff size.

Year 3 HC Data Collection

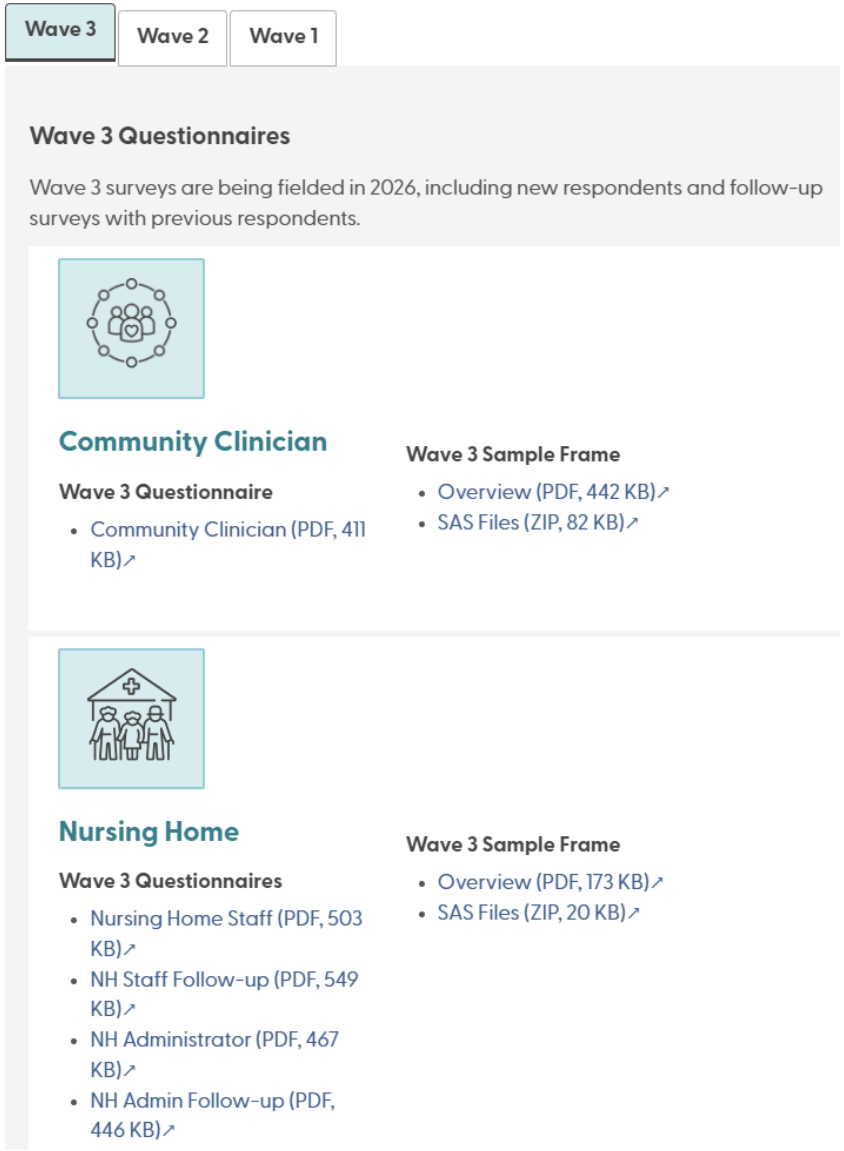
- Recruiting large organizations
  - Unions, training organizations, home care service marketplace sites and chains
  - Offering to share the survey with staff
  - Either unique links for each staff member or “open link” – preference of organization
  - Nonprobability sample
- Respondent Driven Sampling (RDS)
  - *Heckathorn, 1997; Heckathorn, 2002; Bell et al. 2025; Hipp et al., 2019*
  - A version of network sampling
  - If assumptions are met, produces a quality sample of the population

Available Data: Survey Content

- Education, Training and Experience
- Employment Status
- Dementia Care Knowledge, Attitudes, and Practices
- Worker Outcomes
  - For example: job satisfaction, burnout, bullying, injuries
- Demographics

Available Data: Resources

- Check ndws.org for questionnaires, information on accessing data



Available Data: Resources

NDWS survey Restricted Use Files (RUFs) and non-CMS linkable data on MiCDA

1. **Contents:** Full NDWS RUF surveys (including administrator surveys) and the Environment, Process, and
   Quality of Care data sources available to link with surveys
2. **Restrictions:** NDWS and IRB prior approval required; data users must be located in the USA at a US-based institution or company

Thank you!

www.ndws.org • info@ndws.org

References

- Bell, S. A., Kruger, K., Ikari, R., Kuhnmuench, C., Gates, K., & Rosemberg, M.-A. (2025). Addressing Dementia Care Needs During the COVID-19 Pandemic: Perspectives From Home Care Workers. *Journal of Gerontological Nursing*.
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Q&A

Thanks for joining!

Today's presentation will be uploaded to the CaN-D and AWARD websites:

CaN-D's Event Page

AWARD's Event Page