

# Do You Measure What Matters?

## Indicators of a good life across aging and disability LTSS

HCBS Waiver Conference 2019  
Aug 28, 2019

Julie Bershadsky  
Alixé Bonardi  
Mary Lou Bourne

Human Services Research Institute  
Human Services Research Institute  
National Association of State Directors of Developmental  
Disabilities Services

April Young  
Curtis Buhman

National Association of States United for Aging and Disabilities  
Minnesota Department of Human Services



# NASDDDS

National Association of State Directors of Developmental Disabilities Services



# Agenda

- Introductions & Overview of the tools
  - Similarities and differences
  - Goals of each
  - NCI & NCI-AD: Data at the intersect
- Minnesota Highlights using NCI & NCI-AD:
  - Overview of MN agency organization
  - Why MN uses both tools
  - How MN uses NCI and NCI-AD data



# NCI and NCI-AD: Similarities and Differences



## National Core Indicators (NCI)<sup>TM</sup>

- Adults with intellectual / developmental disability (IDD) who receive supports through the developmental disability service system administered by state agencies.
- Tools (5) developed by Human Services Research Institute (HSRI) and the National Association of State Directors of Developmental Disability Services (NASDDDS)
- Began in 1997 - 5 instruments including family surveys, in person Adult survey, and Staff Stability Survey. 46 states plus DC participated

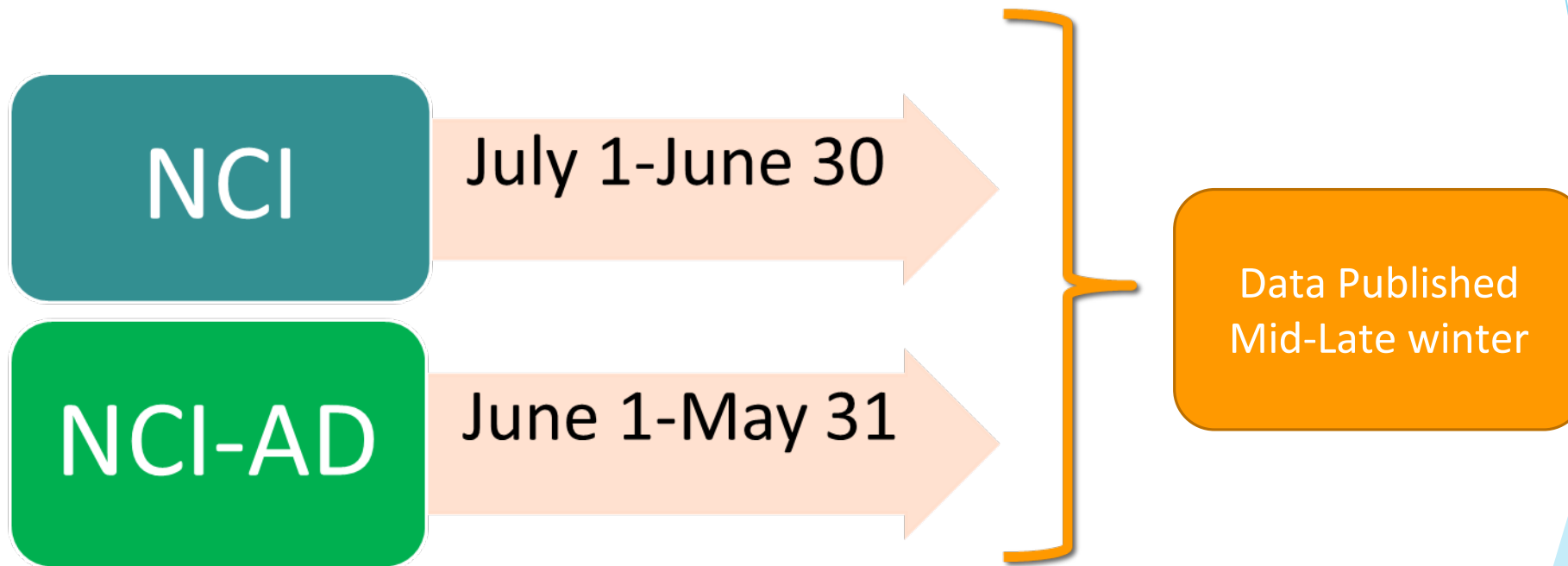
## National Core Indicators- Aging and Disability (NCI-AD)<sup>TM</sup>

- Adults who receive publicly funded long term services and supports because of a physical disability and/or an age-related disability.
- Tool developed by Human Services Research Institute (HSRI) and the National Association of States United for Aging and Disabilities (NASUAD)
- Began in 2015 - 21 states are expected to participate in 2019-20 survey year.

## NCI and NCI-AD: Separate Projects with Similar Features

- ▶ Process and outcome measures collected through face to face encounters
- ▶ Representative sampling
- ▶ Background information (demographics and service history) from state-administrative records
- ▶ Proxy respondents allowed for a portion of the survey
- ▶ Common outcome domains, with some population-specific domains in NCI-AD
- ▶ States elect to participate - data collection completed over a 1 year period.
- ▶ Public reporting of aggregate results

# NCI and NCI-AD: Data Reporting Cycle



# NCI Domains

## **Individual Indicators:**

Community Inclusion  
Choice and Decision Making  
Relationships  
Satisfaction  
Service Coordination  
Work  
Access  
Health  
Medications  
Wellness  
Respect and Rights  
Safety  
Self-Determination

## **Additional Family Indicators:**

Family Involvement  
Community Connections  
Access and Support Delivery  
Information and Planning  
Choice and Control  
Family Outcomes



# NCI-AD Domains

- Community Participation
- Choice and Decision Making
- Relationships
- Satisfaction
- Service Coordination
- Care Coordination
- Work
- Self-Direction
- Access
- Health Care
- Medications
- Wellness
- Rights and Respect
- Safety
- Everyday Living
- Affordability
- Future Planning
- Control
- Person Centered Planning

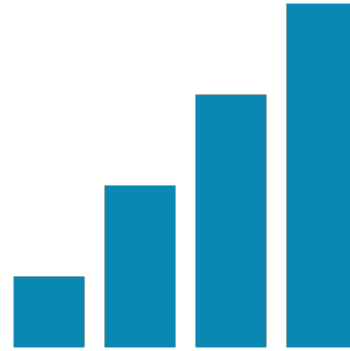
# Goals of NCI and NCI-AD



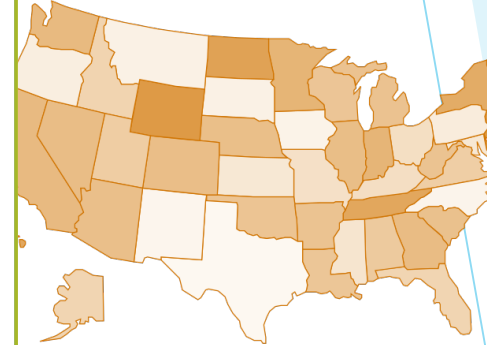
Hear directly from people receiving LTSS



Assess quality of life, service satisfaction, and outcomes of people receiving LTSS

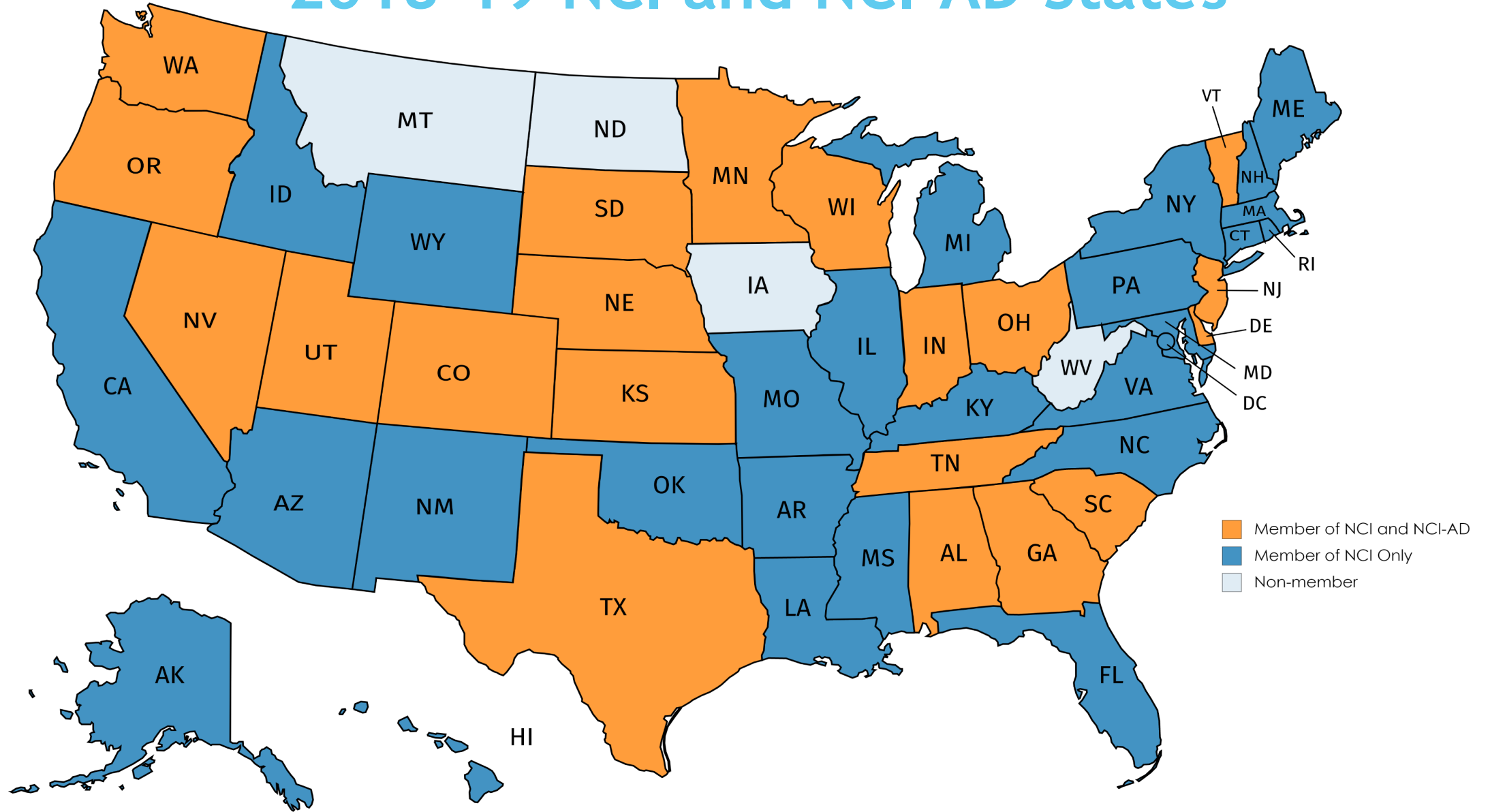


Support state Aging, IDD, and Medicaid agencies in measuring performance of their state LTSS systems



Assist states in improving the quality of services and supports provided

# 2018-19 NCI and NCI-AD States



# NCI & NCI-AD: Data at the Intersect

## Section I: Crosswalk of matching NCI and NCI-AD indicators and corresponding questions

NCI Domain	NCI Indicator		NCI-AD Indicator		NCI-AD Domain	Crosswalk Notes
	Q#	NCI Question	Q#	NCI-AD Question		
Work	<i>Indicator: The proportion of people who have a paid job in the community</i>		<i>Indicator: Proportion of people who have a paid job</i>		Work	<ul style="list-style-type: none"> <li>• NCI reports data from the Background Information (BI) Section, usually collected from administrative and program records; NCI-AD data are self-reported.</li> </ul>
	BI-45	Was this person engaged in a paid individual job in a community-based setting?	55	Do you have a paying job in the community?		
	BI-46	Was this person engaged in a paid small-group job in a community-based setting?				
	BI-48	Was this person engaged in a paid job in a community-based setting that primarily hires people with disabilities?				
	<i>Indicator: The proportion of people who do not have a job in the community but would like to have one</i>		<i>Indicator: Proportion of people who would like a job</i>			<ul style="list-style-type: none"> <li>• NCI reports this item only for those who didn't have a paid community job according to info in the BI Section; NCI-AD reports this item for everyone reporting not having a job.</li> <li>• Note difference in question phrasing: "a job in the community" in NCI; "a job" in NCI-AD.</li> </ul>
	8	Would you like to have a job in the community?	56	Would you like a job?		
	<i>Indicator: The proportion of people who volunteer</i>		<i>Indicator: Proportion of people who volunteer</i>			<ul style="list-style-type: none"> <li>• NCI does not allow proxies for this item; NCI-AD does.</li> <li>• Note difference in phrasing: "volunteer" in NCI; "volunteer work" in NCI-AD.</li> </ul>
14	Do you volunteer?	58	Do you do any volunteer work?			

# NCI and NCI-AD

## 2017-18 Data: Employment

---

	<b>NCI</b>	<b>NCI-AD</b>
<b>Has a paid job in the community</b>	<b>18%<sup>1</sup></b>	<b>2%<sup>2</sup></b>
<b>Volunteers</b>	<b>31%</b>	<b>10%</b>
<b>Would like a job<sup>3</sup></b>	<b>54%</b>	<b>20%</b>
<b>Would like to volunteer</b>		<b>26%</b>
<b>Has community employment as a goal in the service plan<sup>4</sup></b>	<b>29%</b>	
<b>Had someone discuss job options with them<sup>5</sup></b>		<b>18%</b>

# NCI and NCI-AD

## 2017-18 Data: Community

---

	<b>NCI</b>	<b>NCI-AD</b>
<b>Gets to do things that enjoys outside of home as much as wants to</b>		<b>61%</b>
<b>Able to go out and do things that likes to do</b>	<b>85%</b>	
<b>Gets to go out and do things that likes to do as much as wants to</b>	<b>79%</b>	

# NCI and NCI-AD

## 2017-18 Data: Relationships

	<b>NCI</b>	<b>NCI-AD</b>
Can see friends when wants <sup>1</sup>	80%	
Can see/communicate with family when wants <sup>2</sup>	80%	
Able to see/talk to friends and family when wants <sup>3</sup>		88%
Reasons for not being able to see friends <sup>4</sup>	Transportation <sup>5</sup>	
Reasons for not being able to see/talk to friends and family <sup>6</sup>		Accessibility; Transportation <sup>7</sup>
Often feels lonely <sup>8</sup>	10%	
Often feels sad or depressed <sup>9</sup>		14%



# NCI and NCI-AD

## 2017-18 Data: Choice

---

	<b>NCI</b>	<b>NCI-AD</b>
<b>Chose housemates (or chose to live alone)<sup>1</sup></b>	<b>44%</b>	
<b>Able to choose roommate<sup>2</sup></b>		<b>22%</b>
<b>Decides daily schedule<sup>3</sup></b>	<b>85%</b>	
<b>Gets up and goes to bed when wants to</b>		<b>91%</b>
<b>Can eat meals when wants to</b>		<b>82%</b>
<b>Chose staff<sup>4</sup></b>	<b>65%</b>	
<b>Can change staff</b>		<b>73%</b>

# NCI and NCI-AD

## 2017-18 Data: Satisfaction

---

	<b>NCI</b>	<b>NCI-AD</b>
<b>Likes where lives</b>	<b>89%</b>	<b>82%</b>
<b>Reasons for not liking where lives<sup>1</sup></b>	<b>Problems with roommates; Wants more independence<sup>2</sup></b>	<b>Doesn't feel like home<sup>3</sup></b>
<b>Wants to live somewhere else<sup>4</sup></b>	<b>35%</b>	<b>31%</b>

# NCI and NCI-AD

## 2017-18 Data: Rights and Respect

---

	<b>NCI</b>	<b>NCI-AD</b>
People ask before coming into home	91%	
People ask before coming into bedroom	84%	
People ask before coming into home/room <sup>1</sup>		66%
<b>Can lock bedroom</b>	<b>48%</b>	<b>46%<sup>2</sup></b>
Can use phone and internet when wants to	91%	
Can use phone privately when wants to		90% <sup>2</sup>
<b>Others read mail/email without asking</b>	<b>12%</b>	<b>6%<sup>2</sup></b>
<b>Staff treat with respect</b>	<b>93%</b>	<b>91%</b>

# NCI and NCI-AD

## 2017-18 Data: Service Coordination

---

	<b>NCI</b>	<b>NCI-AD</b>
<b>Able to contact<sup>1</sup> case manager when needs to</b>	<b>88%</b>	<b>79%<sup>2</sup></b>
<b>Staff come and leave when they are supposed to</b>	<b>92%</b>	<b>86%</b>
<b>Case manager asks what person wants</b>	<b>88%</b>	
<b>Case manager has talked about services that might help with needs and goals</b>		<b>52%</b>
<b>Was able to choose services as part of service plan</b>	<b>79%</b>	
<b>Can choose or change the kind of services that gets<sup>3</sup></b>		<b>67%</b>

# NCI and NCI-AD

## 2017-18 Data: Self-Direction & Access

---

	<b>NCI</b>	<b>NCI-AD</b>
<b>In self-directed supports option</b>	<b>13%<sup>1</sup></b>	<b>17%<sup>2</sup></b>
Has a way to get places when wants to do something outside of home	84%	
Has transportation when wants to do something for fun outside of home		72%
Has a way to get places that needs to go	93%	
Has transportation to get to medical appointments when needs to		94%



State Experience:

Spotlight on  
Minnesota





# Minnesota: National Core Indicators and National Core Indicators – Aging & Disabilities

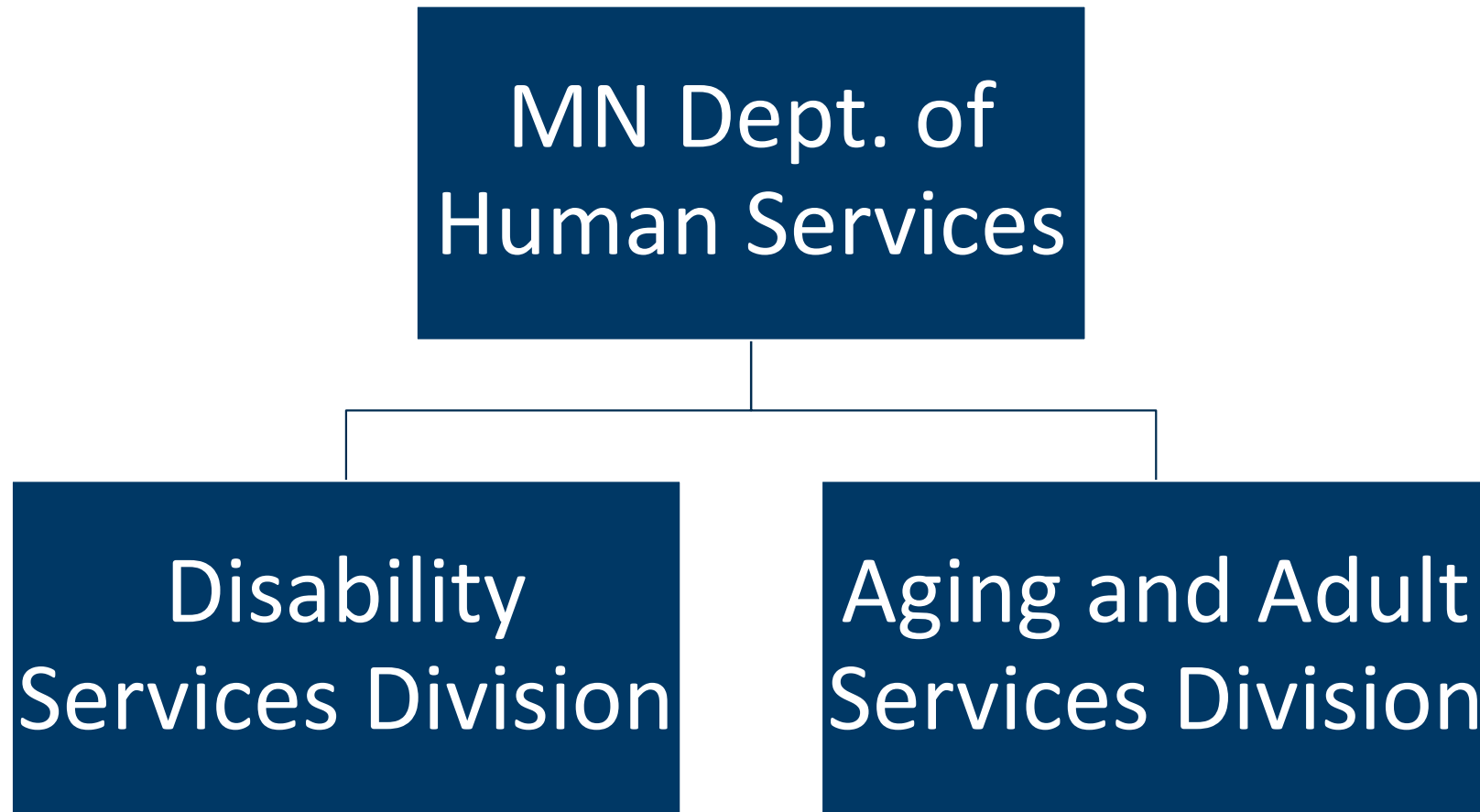
Curtis Buhman | Manager, Disability Services Division

# Who is the MN Department of Human Services (MN DHS)?

- Minnesota's state Medicaid agency
- Work with partners to administer publicly funded long-term services and supports (LTSS)
  - Lead agencies
  - Tribes
  - Managed care organizations



# Disability Services Division & Aging and Adult Services Division



# Minnesota's Olmstead Plan

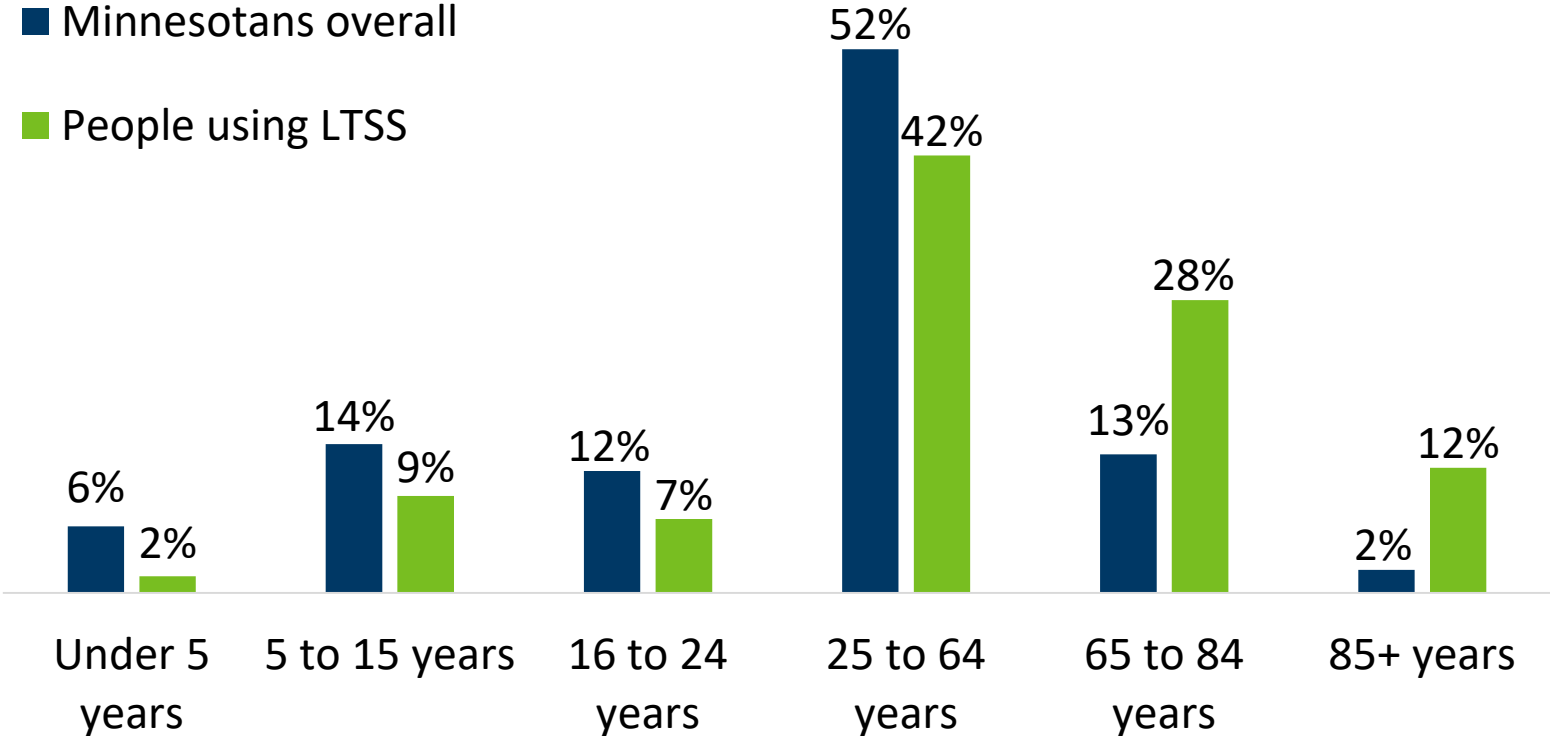
- Increase opportunities for people with disabilities to:
  - Build or maintain relationships with their families and friends
  - Live as independently as possible
  - Engage in productive activities, such as employment
  - Participate in community life.

# How many Minnesotans receive long-term services and supports (LTSS)?

- Total MN population (July 2017): **5.6 Million**
- People receiving LTSS (Jan 2018): **116,593**
- People receiving home and community-based services (HCBS) (Jan 2018): **101,792**
- People in an institutional setting (Jan 2018): **15,128**

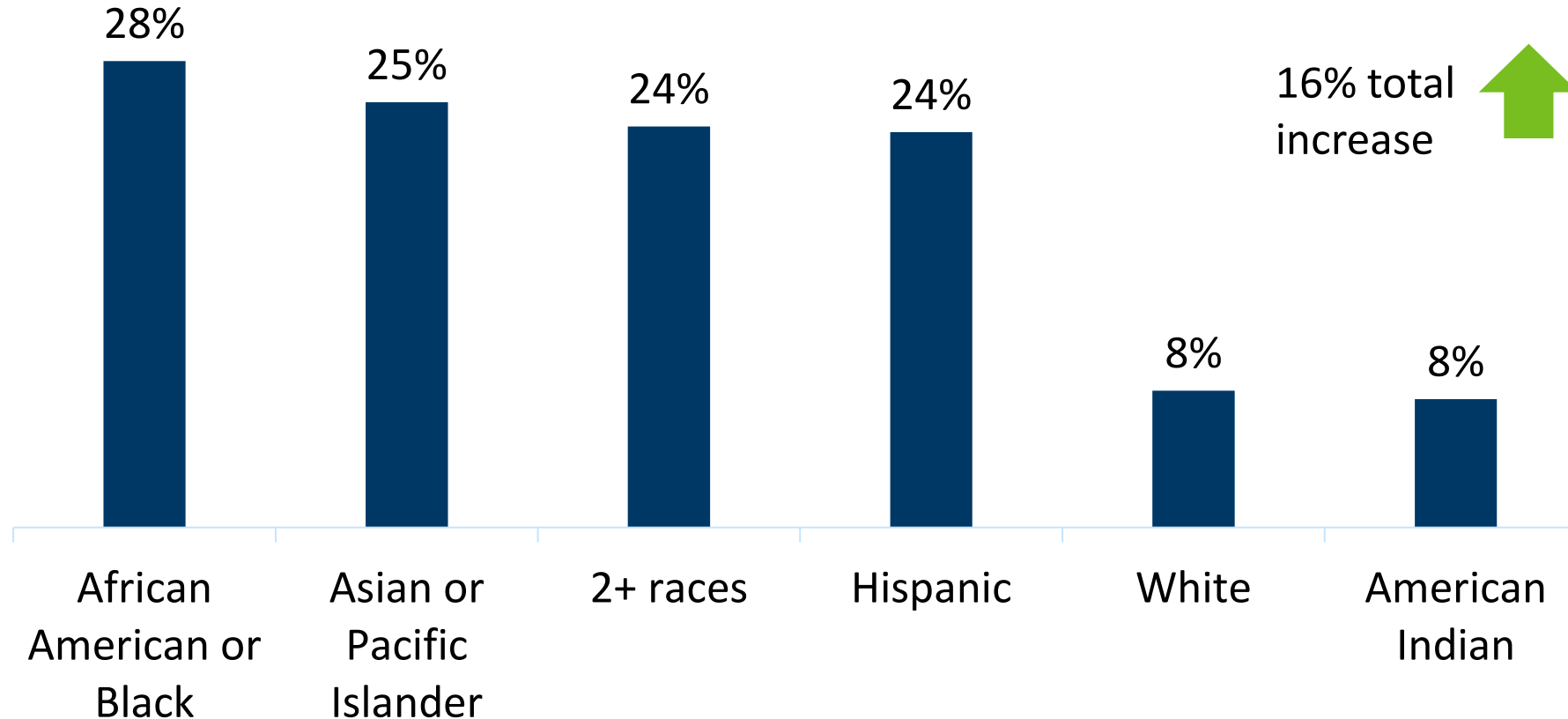
# LTSS demographic trends: Age

## People using LTSS by age compared to Minnesotans overall (2018)



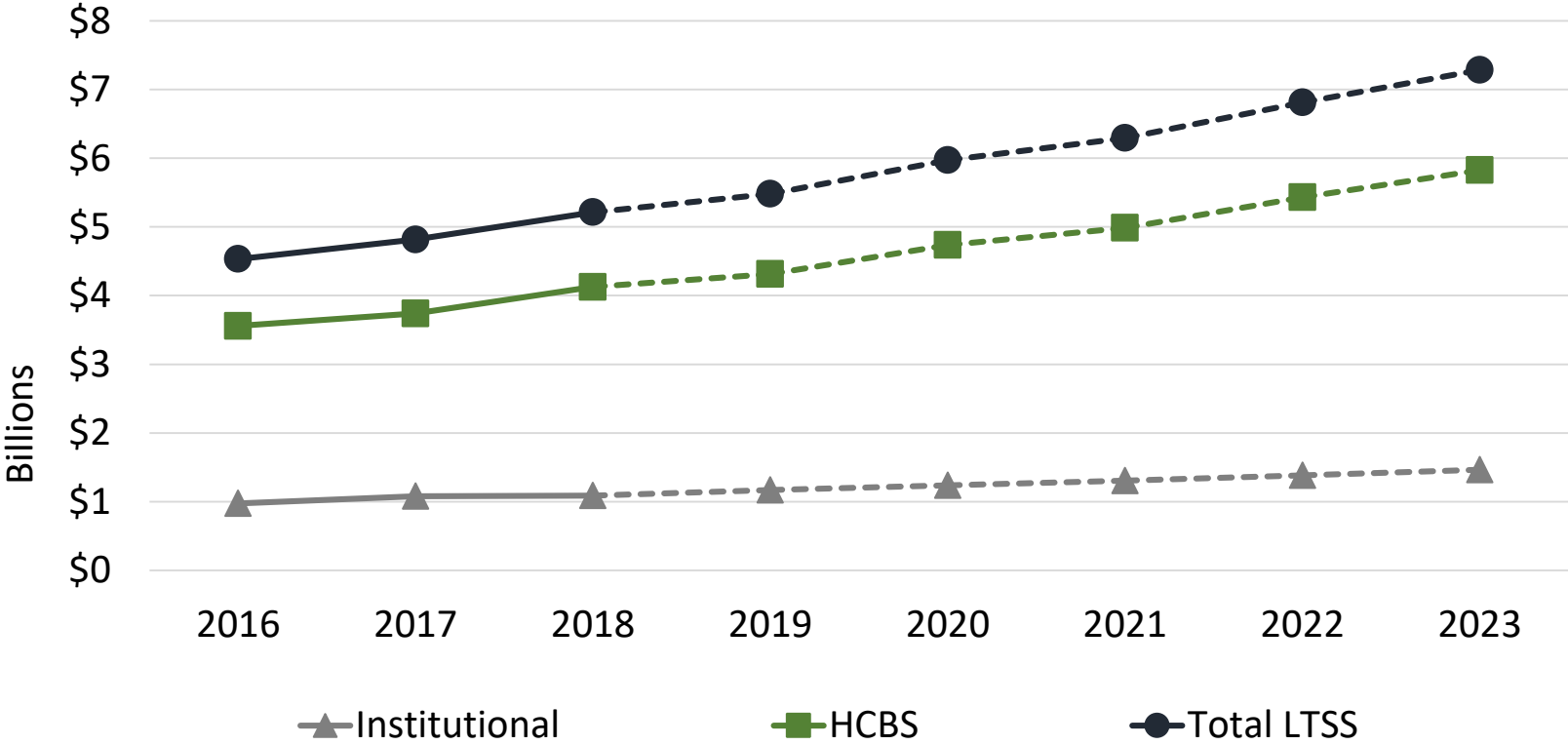
# LTSS demographic trends: Race/ethnicity

Percent increase of HCBS from 2014 to 2018 by race and ethnicity



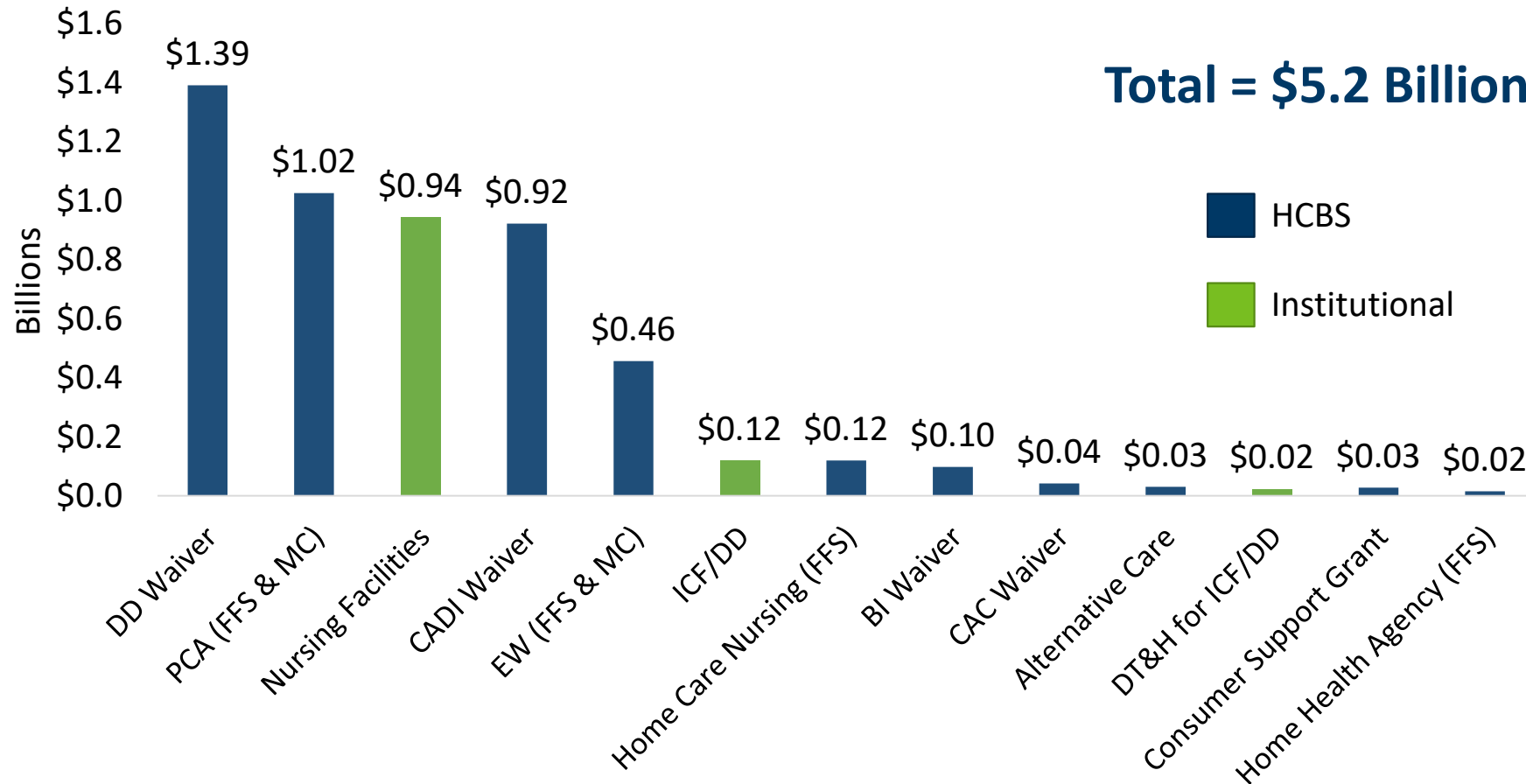
# LTSS spending over time

Total spending for long-term services and supports (in billions), by state fiscal year



# LTSS spending by program

SFY 2018 total LTSS spending (HCBS and institutional)



# Current pressures

- Workforce pressures
- Program and population growth and changes
- New technologies
- Changing preferences
- Federal directives



# Big initiatives

- Improve access to supports for people with complex circumstances/urgent need
- Continued improvement of payment methods including value based purchasing
- Simplify our waiver system including consolidating waiver programs and expanding individual budgeting
- Improve access to transportation for older adults and people with disabilities
- Support efforts to end HIV in Minnesota

# Why does MN Participate in the NCI & NCI-AD surveys?

- Data informed decision making
- Maximize benefit of LTSS to Minnesotans

## Why do we like the NCI & NCI-AD?

- National comparison data with other states
- Surveys were developed for specific populations
- Gathers feedback directly from people
- Independently administered

# How long has MN participated in NCI & NCI-AD?

- NCI

- DSD has participated continuously since 2013
- Participates in the NCI-IPS and Family surveys

- NCI-AD

- DSD and AASD has participated in the NCI-AD since 2014
- Decided to participate to hear from more of the people we support

# Who do we survey?

<b>Survey</b>	<b>Target Population</b>	<b>Method</b>
<b>Aging and Disabilities (AD)</b>	Adults with a physical disability People age 65+	Face to face interview
<b>Adult In-person Survey (IPS)</b>	Adults with intellectual and developmental disabilities (I/DD)	Face to face interview
<b>Adult Family Survey</b>	Families of adults with I/DD living with family	Mailed survey
<b>Family/Guardian Survey</b>	Families or guardians of adults with I/DD not living with family	Mailed survey
<b>Child Family Survey</b>	Families of children with I/DD living with family	Mailed survey

# How much do we survey?

Alternating survey schedule: Approx. completed surveys

- Year 1
  - NCI-AD: 4,000
  - NCI-IPS: 400
  - Family/Guardian: 400
- Year 2
  - NCI-AD: 400 (*adults with physical disabilities only*)
  - NCI-IPS: 2,000
  - Adult Family: 400
  - Child Family: 400

# How do we implement the survey? Partners!

- Develop survey tools and analyze national data
  - National Association of State Directors of Developmental Disabilities Services (NASDDDS)
  - National Association of States United for Aging and Disabilities (NASUAD)
  - Human Services Research Institute (HSRI)
- Implement interviews and surveys in Minnesota
  - Vital Research

# Survey process: Approvals, data pulls, interviewers

- DHS Institutional Review Board (IRB) approval
- Background data pulls
- Interviewers hired and trained

# Survey process: Pre-survey communication

1. NCI & NCI-AD stakeholder resources developed
  - Email announcement
  - [Website](#)
2. Announcement and website sent out to e-lists, stakeholders, and lead agency supervisors
3. Additional communication to field questions for staff who may receive an inquiry about the surveys



# Survey process: The surveys start!

1. People and guardians in sample receive letter about survey.



## Paper surveys

2. Surveys mailed

3. Reminders mailed

## In-person interviews

2. Interviews call people and guardians to ask permission to interview.

3. Approx. 45-minute interview held at place of person's choosing.



4. De-identified data cleaned and analyzed by HSRI for state and national comparison.

# What have we learned from the survey process?

Each year we learn and make improvements to our survey process

- Better communication with stakeholders
- Better data from our systems for the background information
- Better engagement with diverse communities
  - Survey participants
  - Interviewers

# What has MN done with NCI & NCI-AD data?

- Monitoring
  - Example: Olmstead compliance
- Quality improvement efforts
  - Example: Somali elder engagement

# What is MN currently doing with NCI & NCI-AD data?

- Managed Care Organization Workgroup
- NCI-AD factor analysis

# How might MN use NCI & NCI-AD data in the future?

## **We've just scratched the surface**

- Improve results based efforts
- Build analytic capacity
- Use NCI & NCI-AD to inform Minnesotans

# Thank You!

[curtis.buhman@state.mn.us](mailto:curtis.buhman@state.mn.us)




## States Use NCI Data for Both Compliance and Quality Improvement

- ▶ Waiver Performance Measures and Quality Improvement Plans
- ▶ As part of routine quality improvement efforts
- ▶ To inform policy changes and balance health and safety efforts
- ▶ Workforce Stability Data from NCI being used to monitor implementation of wage increases for legislative reports
- ▶ DOJ settlement agreement data includes NCI results in 2 states
- ▶ Workforce stability improvement initiatives cross populations
- ▶ States are preparing to use NCI for routine systemic information on community settings implementation post 2022, and to measure person centered planning regulation implementation

# Example: A Closer Look.....

**Table 69. Able to go out and do the things likes to do in the community as often as wants to**

State	Overall in State	N	ICF/IID and Other Institutional Settings	Community-based Group Residential Settings	Own Home	Parent's or Relative's Home
<b>Significantly Above Average</b>						
<u>State A</u>	87%	398	n/a	86%	88%	86%
<b>Within Average Range</b>						
<u>State B</u>	76%	192	n/a	74%	79%	76%
<b>Significantly Below Average</b>						
 <u>State c</u>	63%	257	n/a	69%	69%	54%
<b>NCI Average</b>	<b>76%</b>	<b>10,553</b>	<b>74%</b>	<b>75%</b>	<b>75%</b>	<b>78%</b>

NCI reveals Opportunities for improvement





NATIONAL  
CORE  
INDICATORS™

## NCI and NCI-AD Data Offers View into Variation and Opportunities for Improvement

- ▶ States set priorities for overall Long Term Service and Support Systems
- ▶ Priorities identify measures of importance for tracking
- ▶ Comparisons in populations must take into account service system variations
- ▶ Opportunities to identify differences, variations and areas for reasonable comparisons
- ▶ Workforce Stability provides opportunities to share improvement efforts through the NCI Staff Stability Survey



[www.nationalcoreindicators.org](http://www.nationalcoreindicators.org)



[www.nci-ad.org](http://www.nci-ad.org)

## Contacts:

Julie Bershadsky	<a href="mailto:jbershadsky@hsri.org">jbershadsky@hsri.org</a>
Alixé Bonardi	<a href="mailto:abonardi@hsri.org">abonardi@hsri.org</a>
Mary Lou Bourne	<a href="mailto:mlbourne@nasddds.org">mlbourne@nasddds.org</a>
April Young	<a href="mailto:ayoung@nasuad.org">ayoung@nasuad.org</a>
Curtis Buhman	<a href="mailto:curtis.buhman@state.mn.us">curtis.buhman@state.mn.us</a>



Human Services  
Research Institute

# NASDDDS

National Association of State Directors of Developmental Disabilities Services



**mi** DEPARTMENT OF  
HUMAN SERVICES