

What Do NCI Data Tell Us About Self-Advocacy?



**NATIONAL CORE
INDICATORS**
NASDDDS & HSRI



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July 18, 2019

National Core Indicators

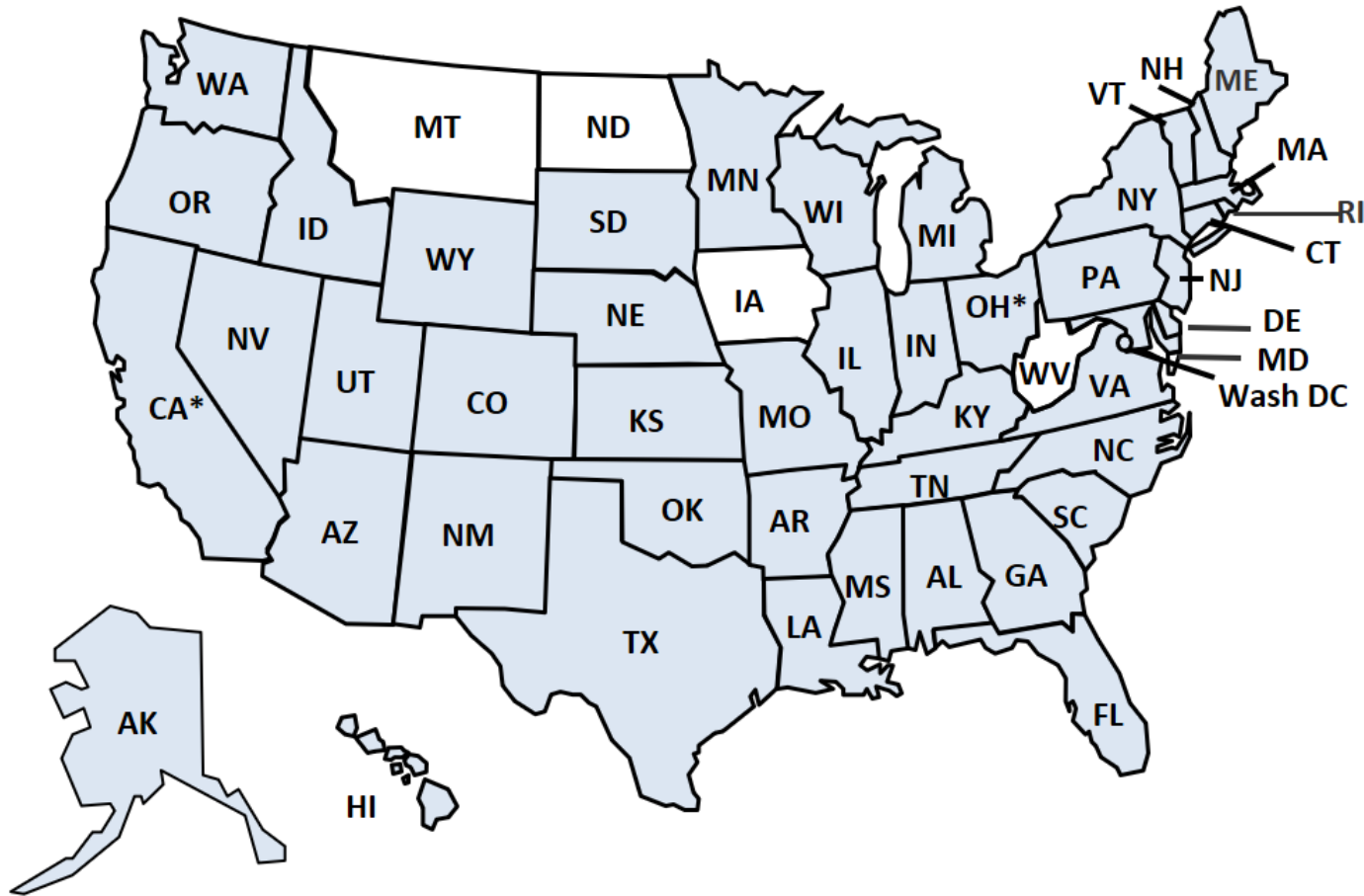
National Overview and State Context

What is NCI

- NCI began in 1997
- Collaboration between:
 - The National Association of State Directors of Developmental Disabilities Services (NASDDDS) and
 - Human Services Research Institute (HSRI)
- Voluntary effort by public developmental disabilities agencies to measure and track their own performance
- Currently 46 states and Washington D.C. represented



NCI Participating States



*Includes sub-state entities



Survey Tools



*Formerly the Adult Consumer Survey (ACS)



NCI Purpose



Establish a nationally recognized set of performance and outcome indicators for DD service systems



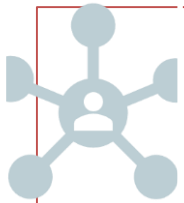
Use valid and reliable data collection methods & tools



Report state comparisons and national benchmarks of system-level performance



Person-Centered Approach



Keyed to important person-centered outcomes



Person's perspective is priority



Guided conversation



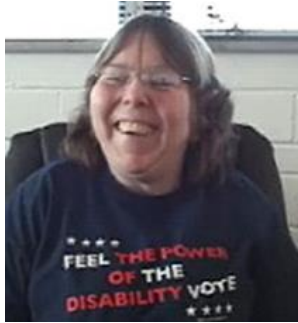
Person chooses when and where to meet



A brief history and context

Self-Advocacy

Heroes of the Self-Advocacy Movement



Nancy Ward, first chair of Self Advocates Becoming Empowered, 1990



Tia Nellis, Active in SABE, advocated for voting rights, consultant UIC



James Meadours, advocate for people who have been sexually abused



Chester Finn, early SABE Leader, active in New York



Liz Weintraub, Member of the President's Committee on Intellectual Disability, and host of Tuesday's with Liz



TJ Monroe, Member of the President's Committee on Intellectual Disability, Employment advocate



Mission of Self-Advocates Over Time

- Close institutions
- Get rid of the “R” word
- Expand self-direction
- “Nothing about us without us”
- Normal life, relationships, employment
- Reduction of guardianship



Selected FL findings 2017-18 IPS

Self-Advocacy

In-Person Survey

- Face-to-face meeting with person receiving services (at least one beyond case management)
- Three parts of the survey:
 - Background information – demographics and personal characteristics (information mainly comes from records)
 - Section I – subjective questions only person can answer
 - Section II – objective questions can be answered by a proxy if needed

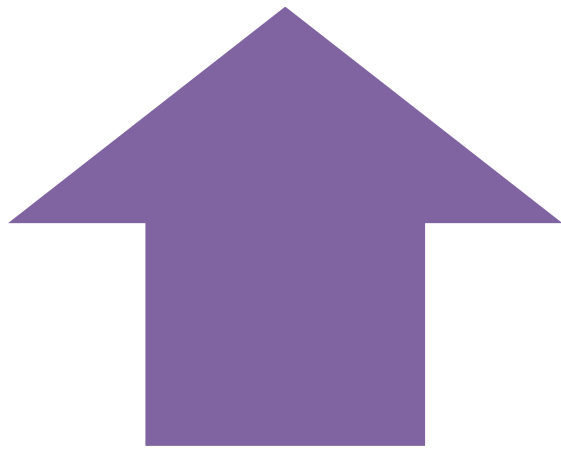


Notes and Limitations on Comparisons

- Some comparison groups have small N's
 - The N can affect data and small N's should be viewed with caution
- Not all outcomes show significant differences between groups
- Significance is noted at:
 - .05 with one asterisk (*)
 - .01 with two asterisks (**)



Has Attended a Self-Advocacy Group, Meeting, Conference or Event or Chose Not To



24%
NCI

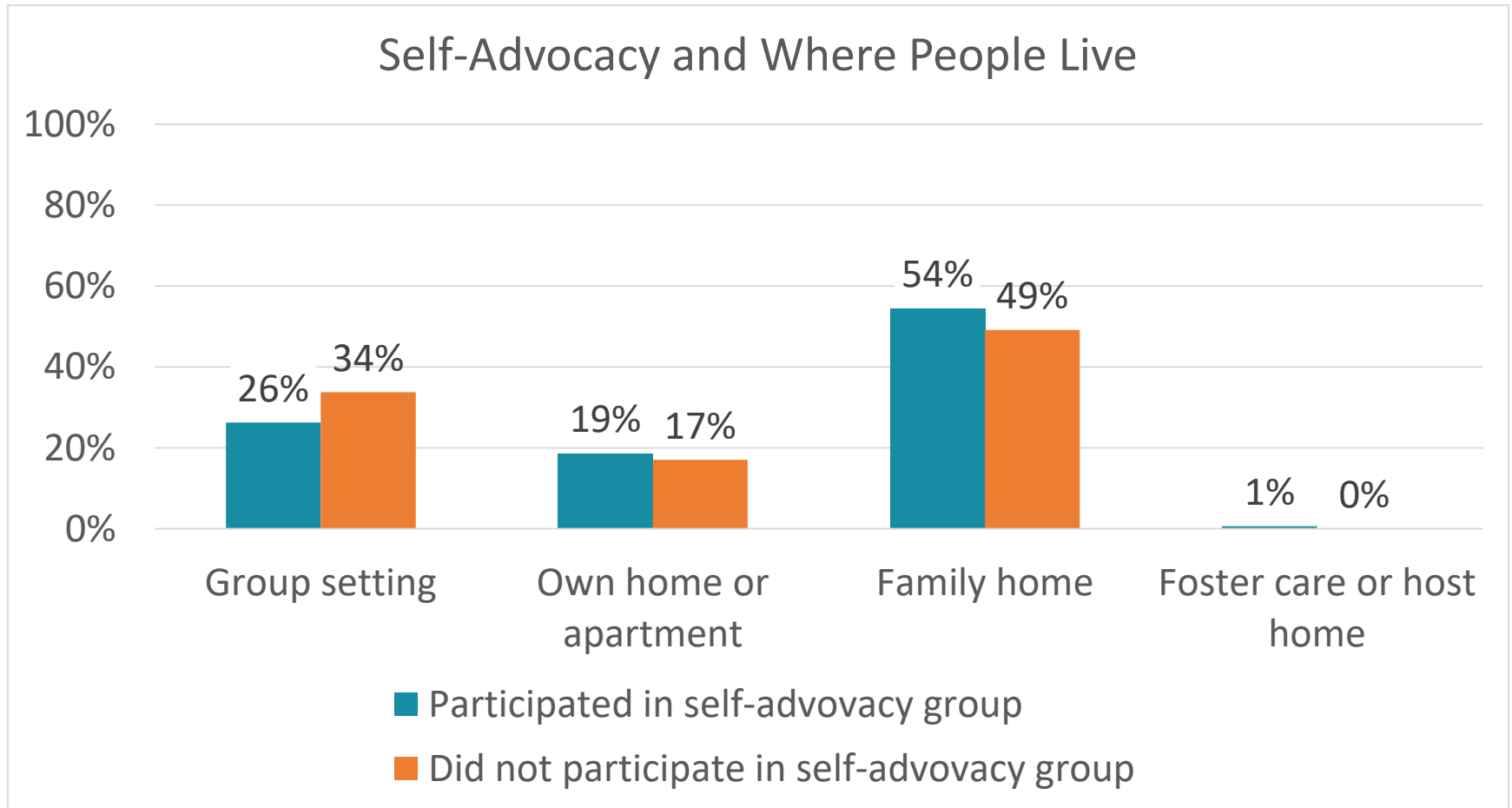


20%
FL*

*Significantly lower than NCI Average



Where People Live



Communication Among Those Who Attended a Self-Advocacy Group....

English*

was the preferred language for

96%

of those who attended a self-advocacy

4%

had another preferred language

Preferred Means of Communication**

Spoken

84%

Gestures

14%

Other

2%

*Significant at .05

**Significant at .01



Relationships and Volunteering

Has Friends

- **85%** attended self advocacy group
- **82%** did not attend self advocacy group

Can See Friends

- **84%** attended self advocacy group
- **78%** did not attend self advocacy group

Volunteers*

- **32%** attended self advocacy group
- **20%** did not attend self advocacy group

**Significant at .01



Voting**



52%

of those who attended a self-advocacy group also reported they

Voted in a local state or federal election

33%

Of those who did not attend a self-advocacy group also reported they have ever voted

**Significant at .01



Ways to Encourage Self-Advocacy

- Develop Speaker's Bureau to give people with ID/DD experience in public speaking
- Ensure that wherever self-advocates are included on boards, etc., that they have adequate support and aren't just tokens
- Assist self-advocacy organizations to raise funds
- Educate providers and family members on the importance of self-advocacy
- Other ideas?



Discussion and Questions

