



**National Core Indicators:
Listening to People with
Disabilities for 20 Years
HCBS Conference, Baltimore
MD Aug. 29, 2017**

Valerie Bradley, President Emerita HSRI

**Nancy Thaler, Director of Pennsylvania Office
of Developmental Programs**

Mary Lou Bourne, Director of NCI, NASDDDS

What is NCI?



NATIONAL CORE
INDICATORS

- NCI is a voluntary effort by public developmental disabilities agencies to measure and track their own performance.
- Collaboration began in 1997
- Currently 46 states and Washington D.C. represented plus 22 sub-state entities
- Coordinated by HSRI and NASDDBS



NASDDBS

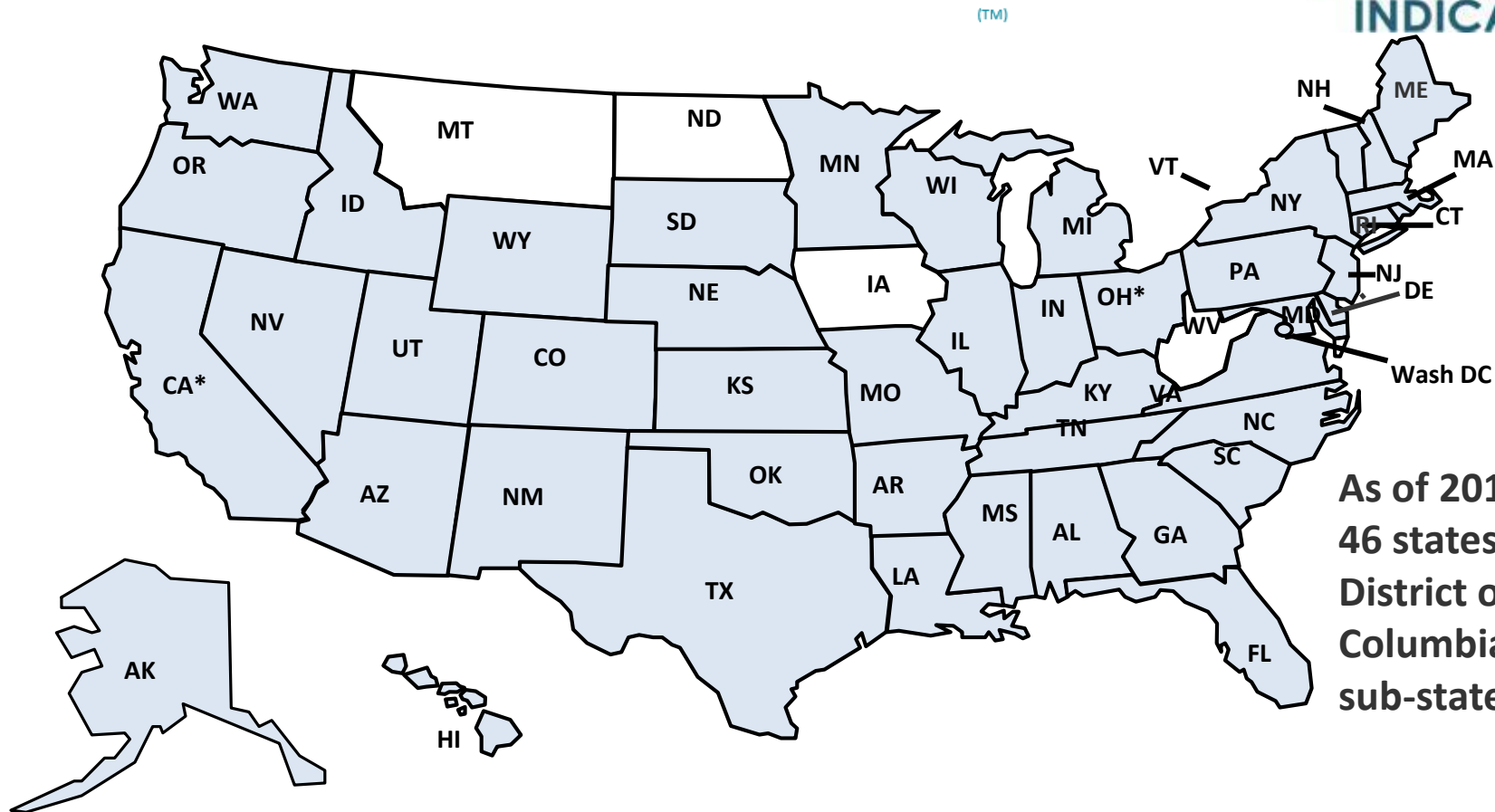


Human Services
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Where is NCI Today?



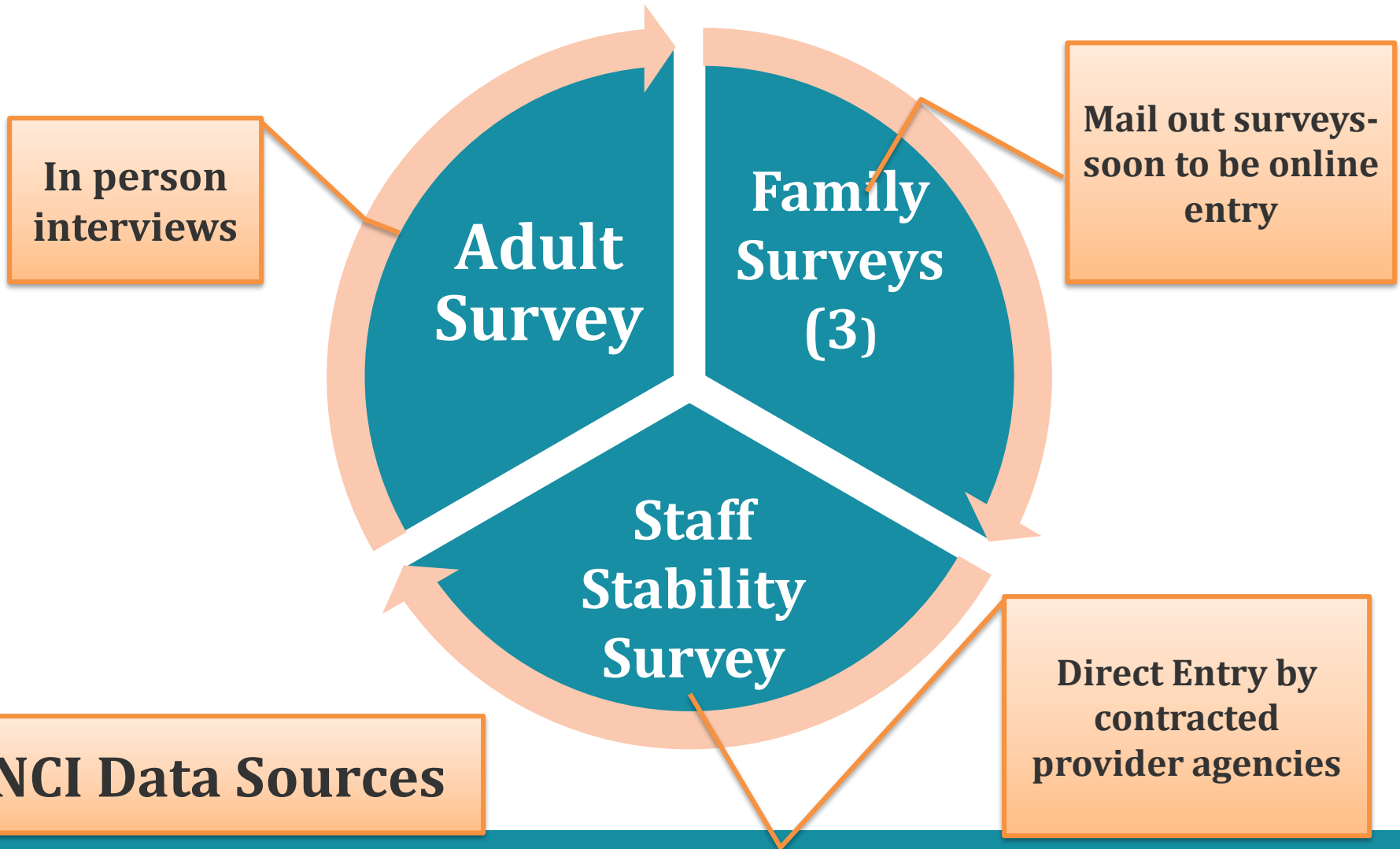
NATIONAL CORE INDICATORS



**As of 2016-17:
46 states, the
District of
Columbia and 22
sub-state regions**



How Does NCI Collect Data?



NCI Domains



Individual Outcomes

- Employment
- Community Inclusion
- Choice & Decision making
- Personal Relationships
- Self Determination



Family Outcomes

- Choice and Control
- Family Involvement
- Information & Planning
- Access, community connections
- Crisis Response

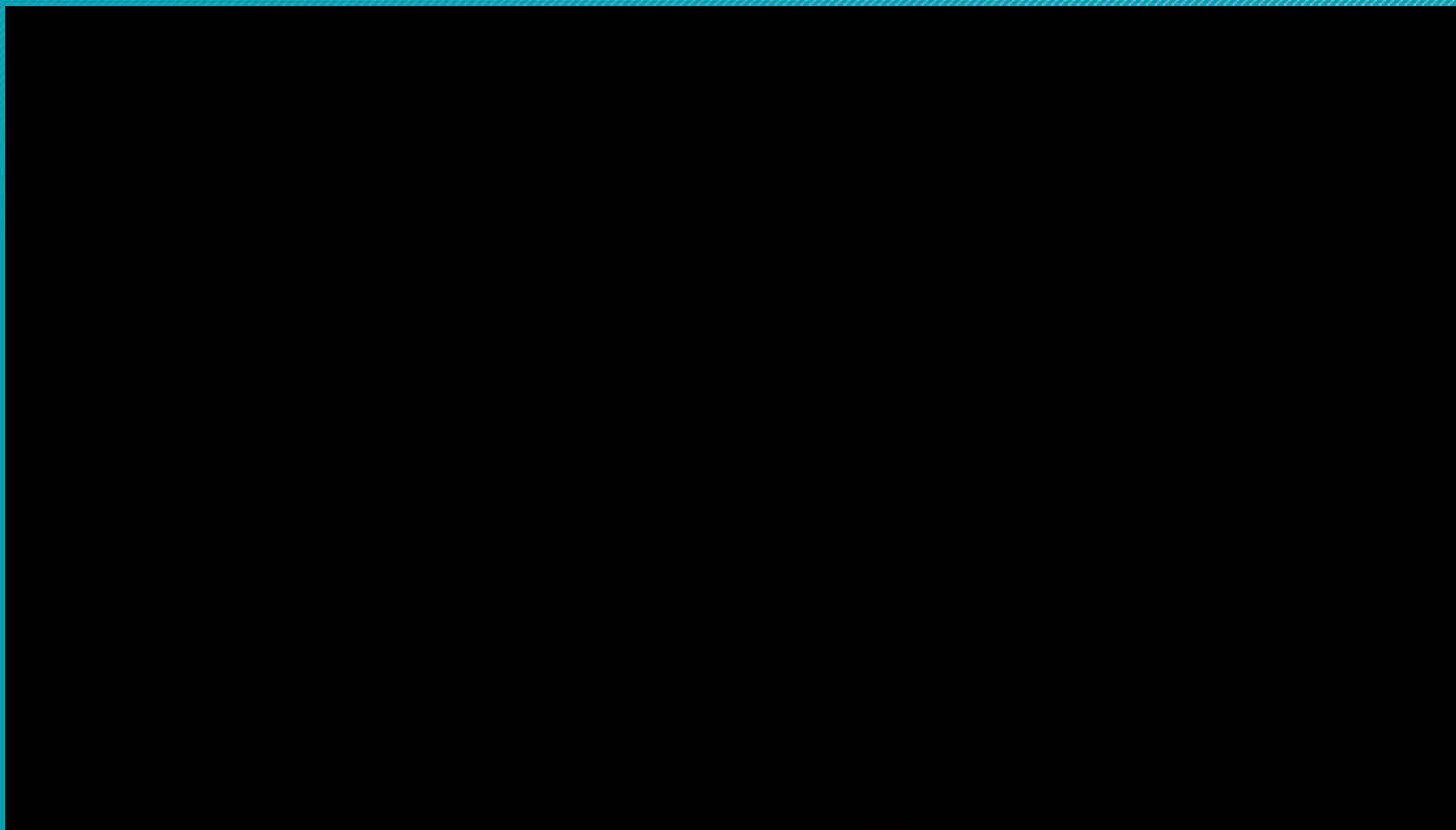


Health, Welfare, System

- Health and Welfare
- Respect for Rights
- Medications
- Safety
- Service Coordination
- Staff Stability



From the Perspective of People who use I/DD services: Why is NCI Important?





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Antecedents to NCI

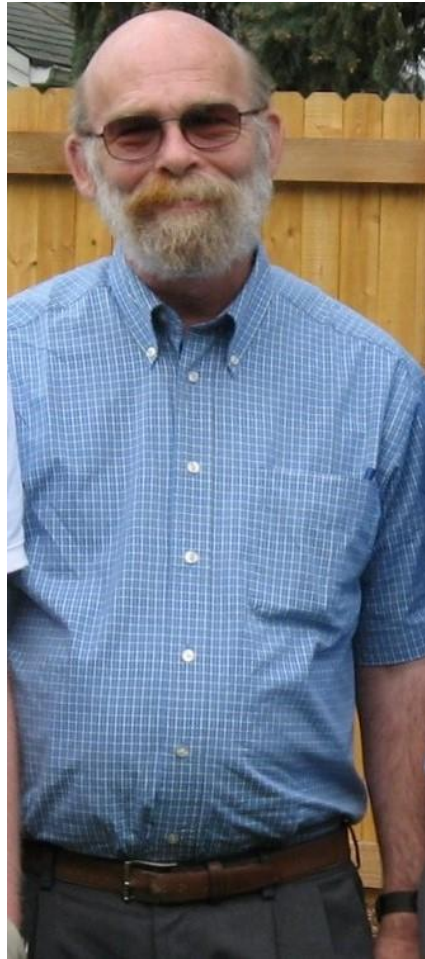
- Growing interest in outcomes as a means to understand the performance of IDD systems
- Pressure to block grant Medicaid (sound familiar?) and a fear that the particular concerns of the IDD system would be swamped
- Recognition of the increasing complexity of the IDD system as the community system began to significantly outpace institutional services
- Rising expectations about the ability of people with IDD to live real lives in the community
- Interest in transparency and the importance of making performance information public



Some of the Original “Fathers” of NCI



Bob Gettings, Former Director of the National Association of State Directors of Developmental Disabilities Services



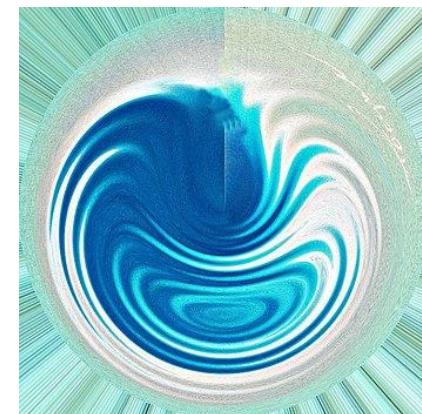
Gary Smith, former policy director at NASDDDS



John Ashbaugh, Former Vice President of HSRI



Early Stirrings



- Formation of a Steering Committee made up of 13 state representative
 - facilitated by NASDDDS and HSRI in 1997
- Development of overarching goals in the form of domains including employment, community inclusion, relationships, family support, choice, and health and safety
- Commitment to solicit the voices of people with disabilities and their families – not just process measures
- Identification of indicators – how would you know it if it happened?
- Creation of data collection instruments



Six States Stepped Forward



- Six states volunteered to field test the tools in 1998
- Administration of the Adult Consumer Survey showed inter-rater reliability and test-retest reliability, and indicated the need to revise some of the questions
- The ICAP was administered in order to design risk adjustment criteria
- Based on the field test, NASDDDS members agreed that the Core Indicators Project (now NCI) would go forward.
- Numbers of member states continued to grow over the next two decades from the original 6 to 46 including the District of Columbia plus 22 sub-state entities
- In the last round of Adult Surveys, there were 17,682 respondents; the largest ongoing data base of outcomes of people with disabilities probably in the world.

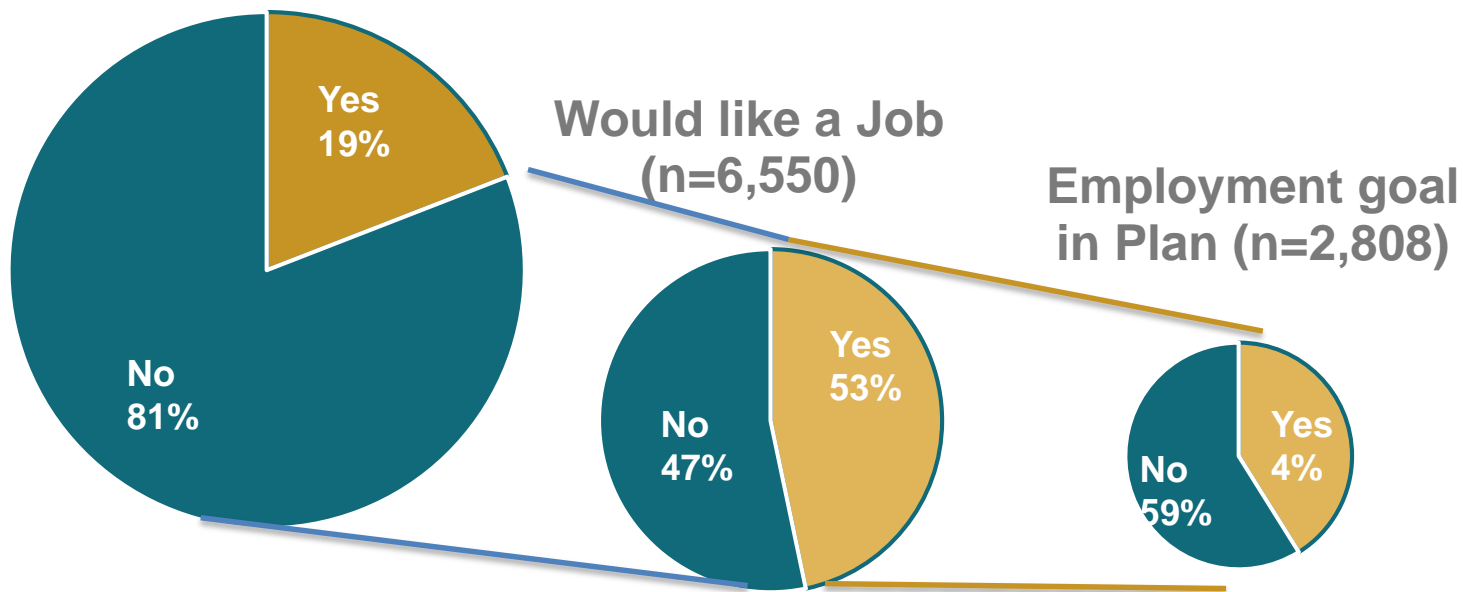




**What do Self-Advocates
Tell Us About What's
Important to Them?**

2015-2016 NCI Adult Survey

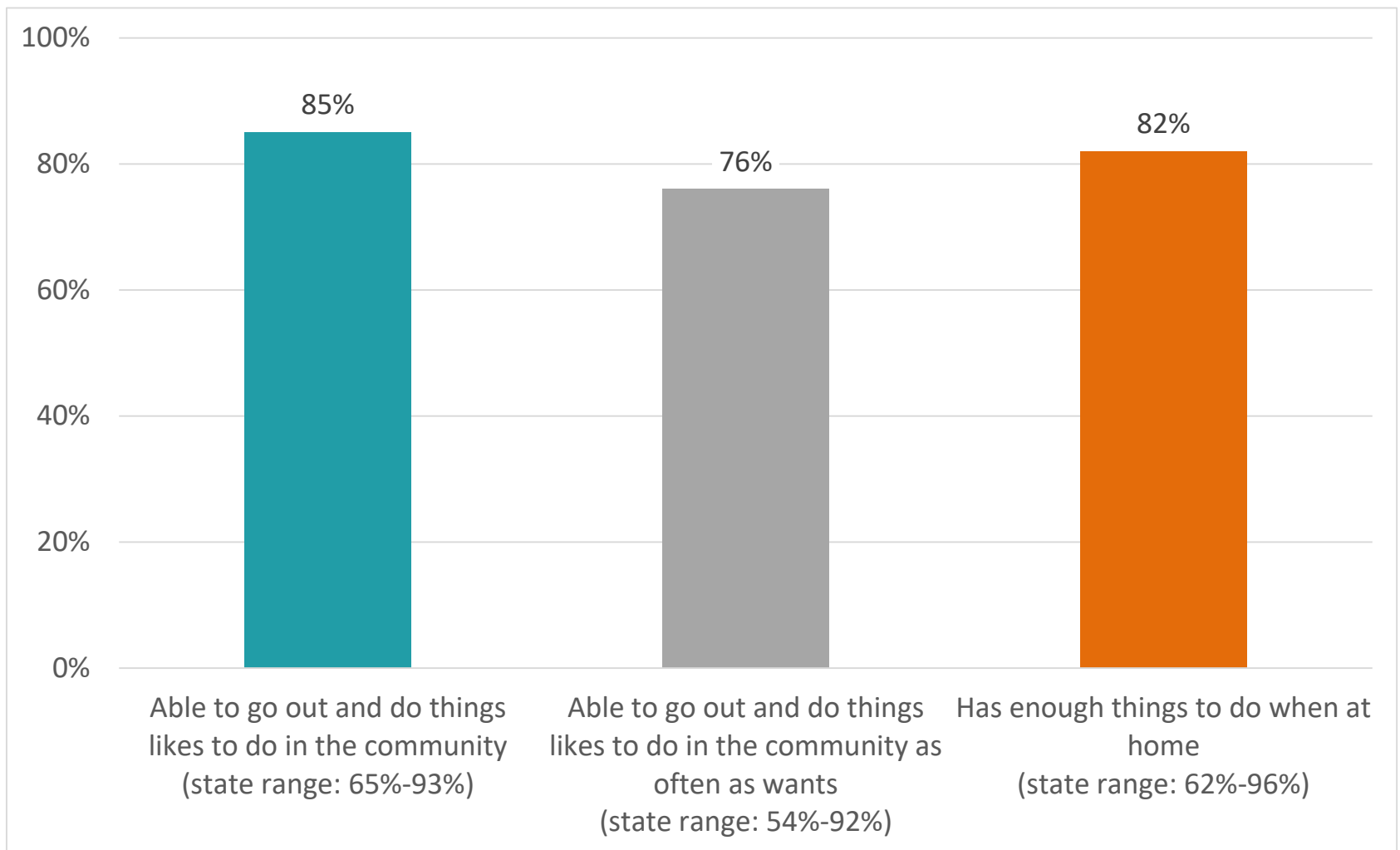
Has a Job (n=16,375)



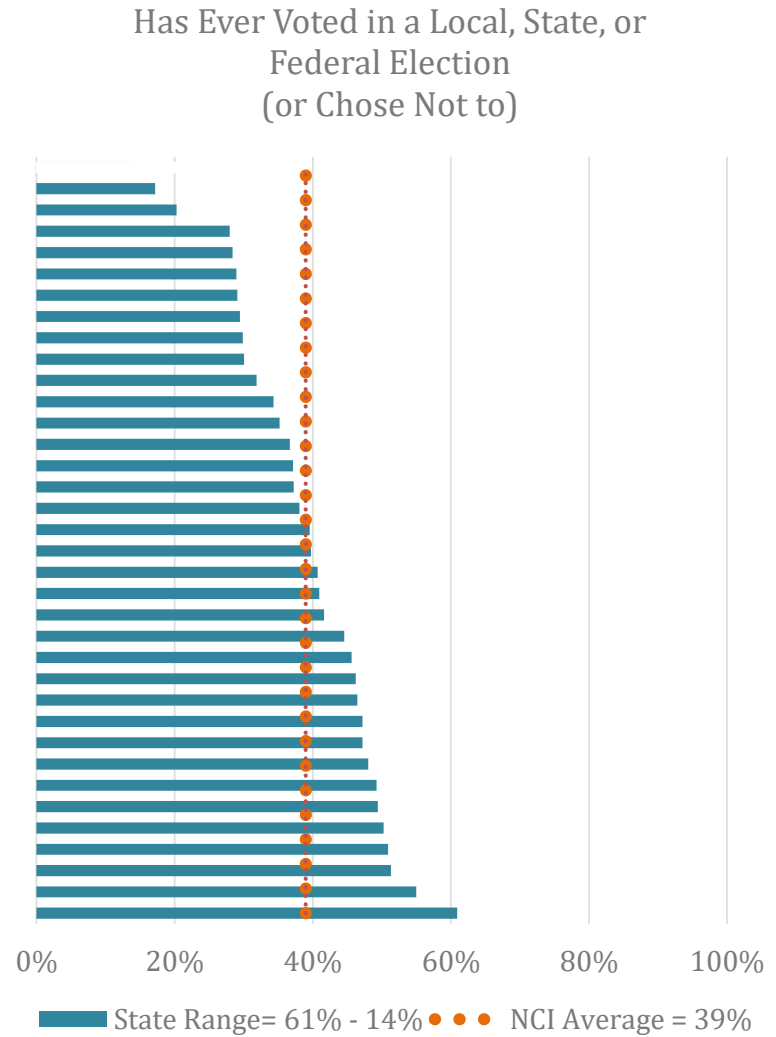
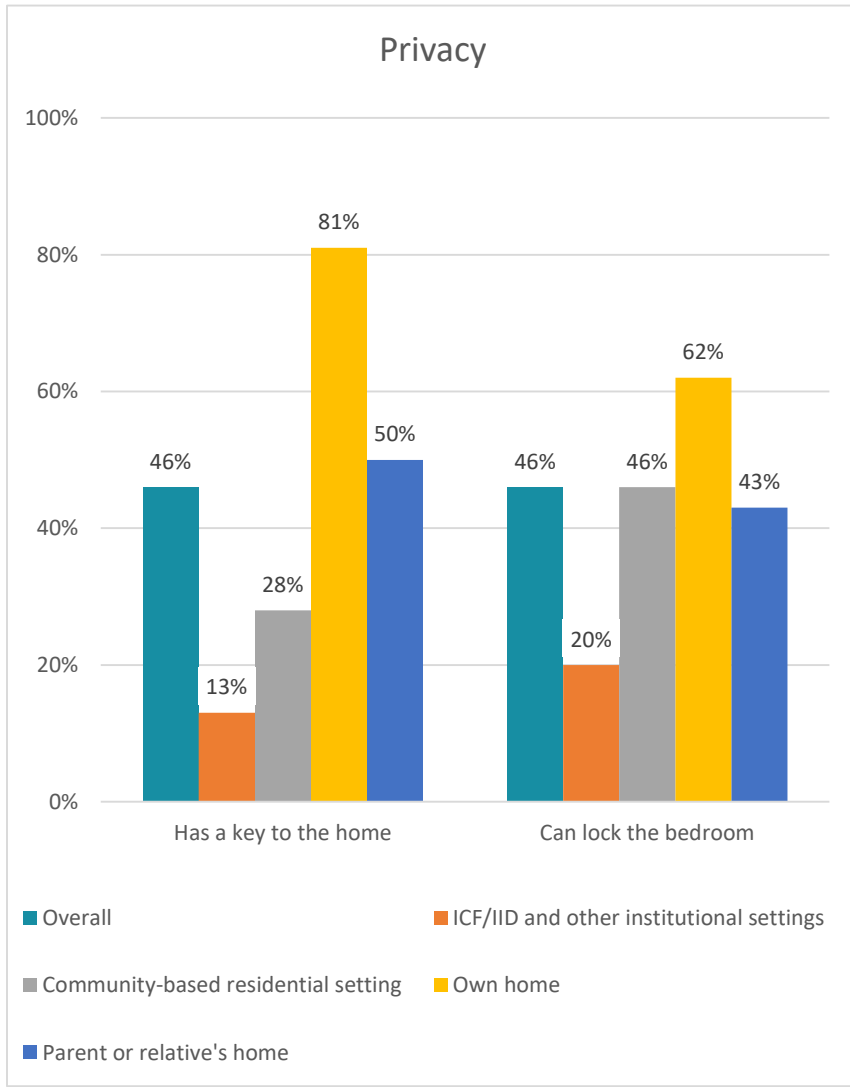
24% took classes, training, or did something to get a job or get a better job



Community Participation and Leisure



Privacy and Rights





92%

Services and supports help person live a good life





**What Changes Have Taken
Place Over the Past 20
Years?**

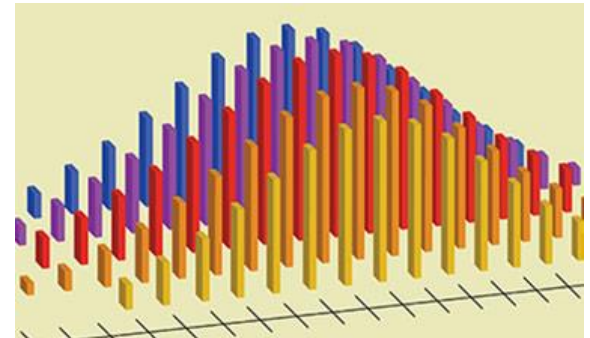
Enhancements to NCI

- Refinements of the Adult Survey to include more information on employment, wages, health, and self-direction
- Addition of Child/Family Survey
- Advent of Data Briefs on key topics
- Launch of the Sarah Taub Webinar Series
- Development of the Staff Stability Survey
- Circulation of the Fortnightly newsletter
- Training materials and videos
- Annual Meeting of State NCI Coordinators



Recent Data Briefs

- What Do NCI Data Show About Respondents Who Need Support for Self-Injurious Behavior? (Bradley, Hiersteiner and Rotholz – May 2017)
- What Do NCI Data Show About Friendship and Life Outcomes for Adults With Intellectual and Developmental Disabilities? (Giordano, Hiersteiner, and Pell, September 2016)
- Working in the Community: The Status and Outcomes of People with Intellectual and Developmental Disabilities in Integrated Employment (Hiersteiner, Butterworth, Bershadsky, and Bonardi, May 2016)



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Why Pa Helped to Found NCI in 1997

- The HCBS waiver program was growing nationally.
- There was controversy about the quality of community services
- State legislatures were starting to ask questions about “these waivers.”
- There was absence of any measures or data to defend the program.
- If “we”, the states, don’t create a set of quality measures, someone else will.



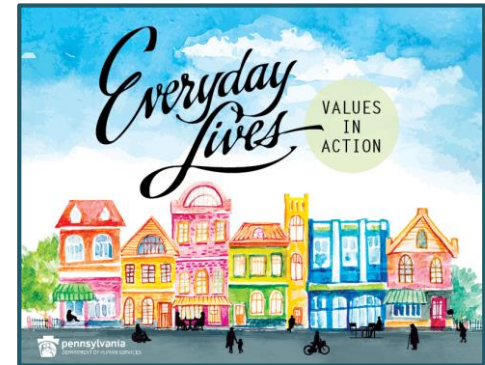
Why Pa. Continues to be an NCI State

- It provides data to measure quality from the experience of the people we serve
- It is standardized and tested for validity and we could never create the same caliber instrument
- Because 46 states and DC use NCI, we can compare our performance to other states
- It is a way to engage consumers and families in measure quality
- Stakeholders do not squabble with the findings because of the integrity of the instrument – they embrace the results and we focus on making things better.



How We Use it

- 48 Independent Monitoring for Quality (IM4Q) teams conduct about 5,500 interviews each year.
- The teams are consumers, families, advocates and citizens in the community.
- The results are used with our Advisory Committee to measure progress and plan improvements for the 12 recommendations in our Everyday Lives Plan.



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Director, National Core Indicators and Quality
Assurance
NASDDDS



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How do we let others know the results?

- Reports –
 - National
 - State
 - At-A-Glance
 - User Friendly
- Webinars
- Data briefs
- State Specific Reports/Special Studies



NCI Reports



National Core Indicators™ AT-A-GLANCE Report

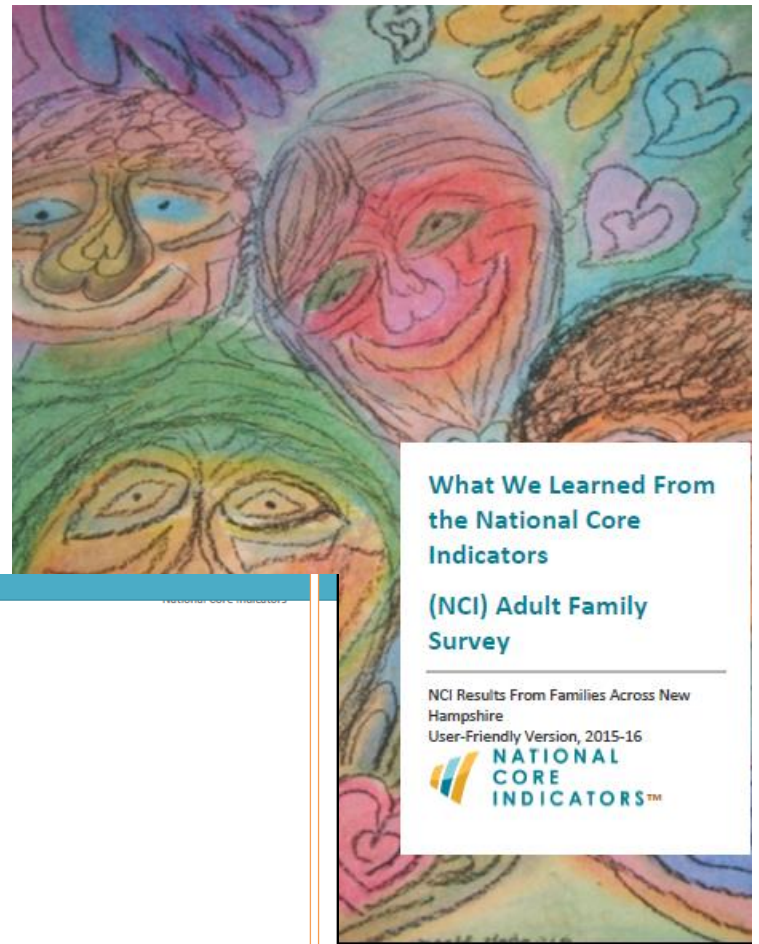
Selected Findings From the 2015-16 Surveys



National Core Indicators™ Adult Consumer Survey

Alabama Report

2015-2016 Data



What We Learned From
the National Core
Indicators

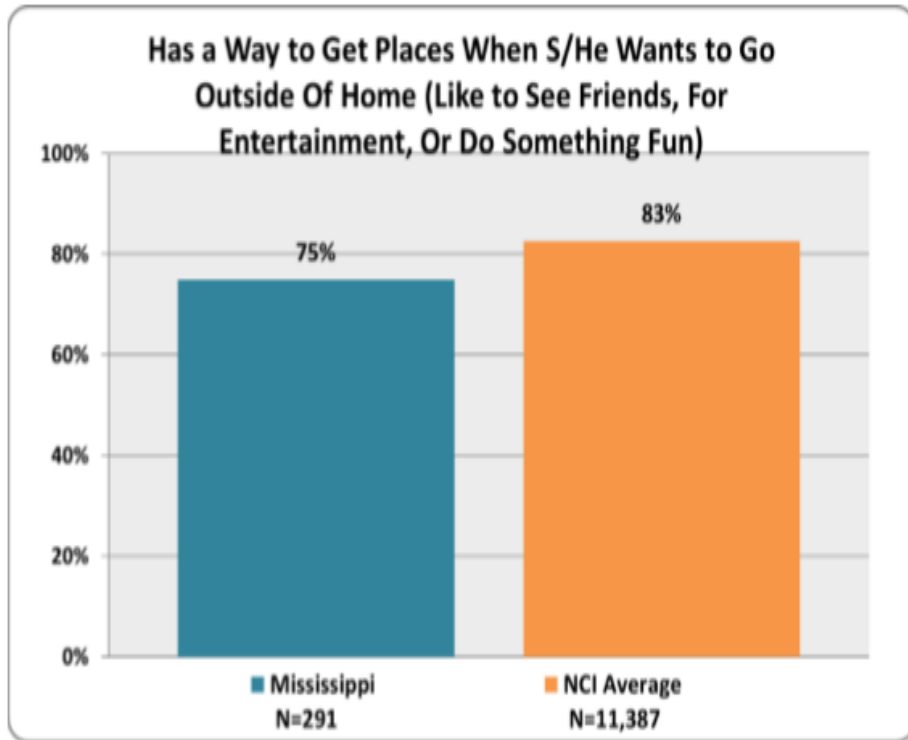
(NCI) Adult Family
Survey

NCI Results From Families Across New
Hampshire
User-Friendly Version, 2015-16

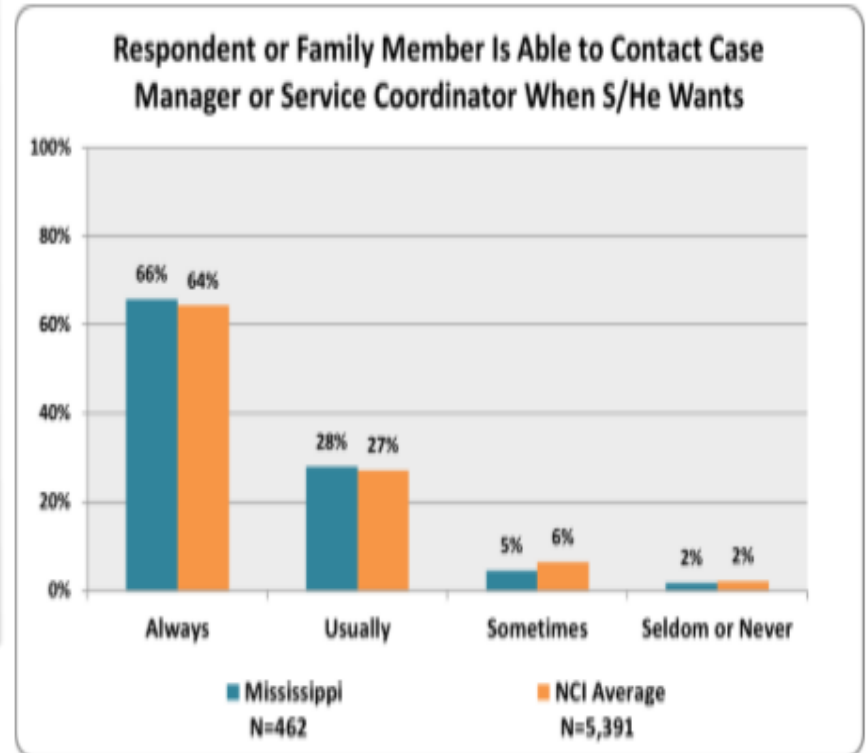


State Reports

ACS

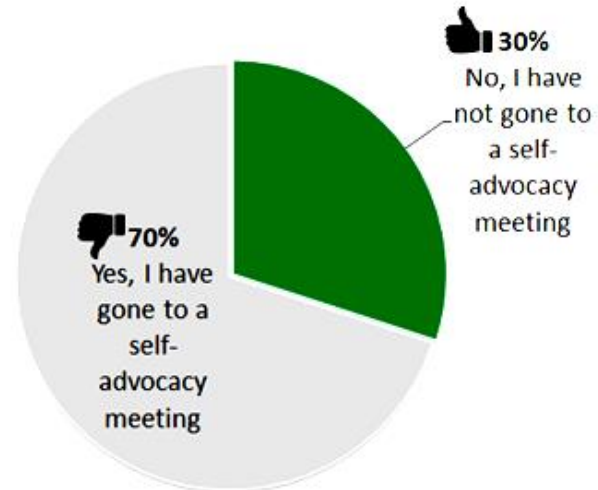


AFS



User-Friendly Report

Have you gone to a self-advocacy meeting?



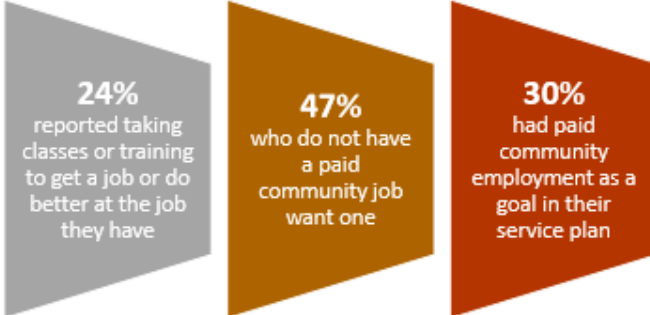
NCI tells us 3 out of every 10 people said they **have gone to a self-advocacy meeting.**



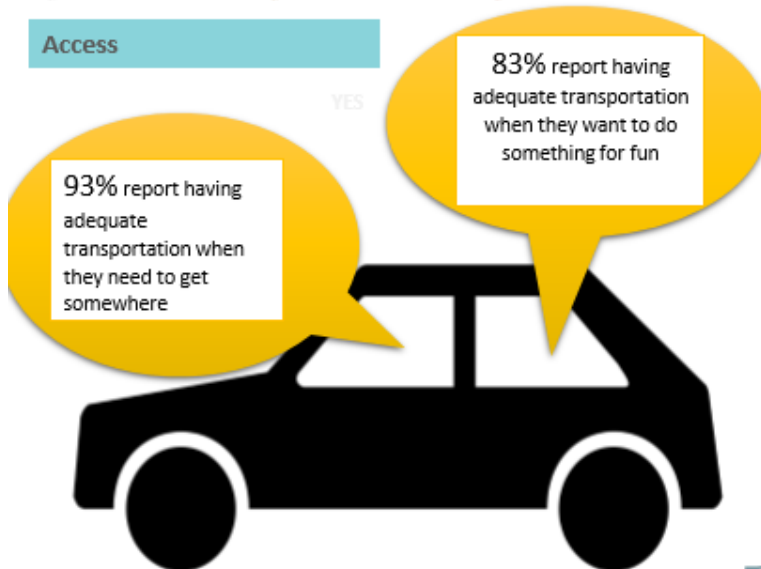
At-A-Glance Report

Employment

19% of respondents were reported to have a **paid community job (Individual and or group)**

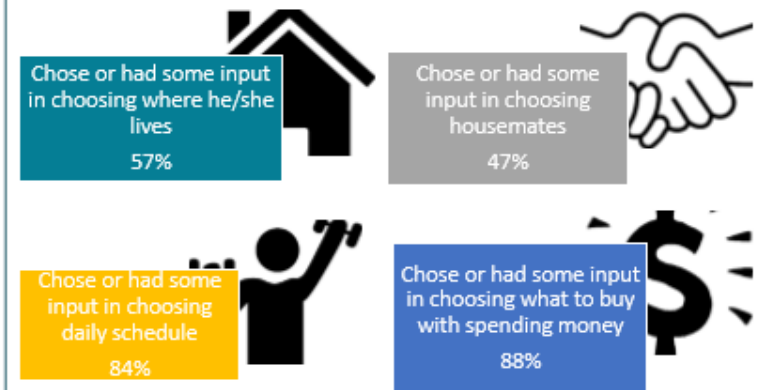


Access



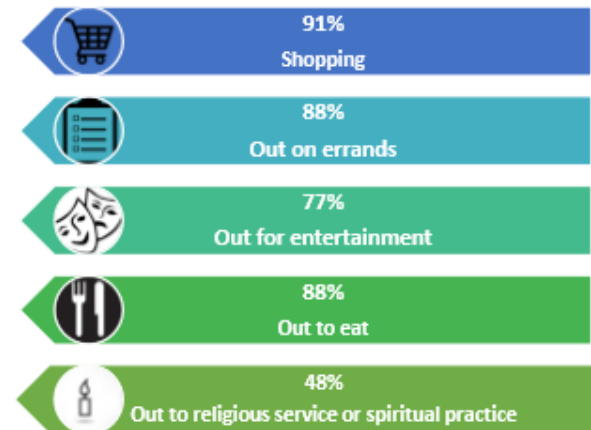
Choice, Decision-making and control

Adjusted variables



Community Inclusion, Participation and Leisure:

Percentage of respondents that report having done the following activities in the community at least once in the past month



2015-16 Adult Consumer Survey

NATIONAL CORE INDICATORS™



Data Briefs

- Data Briefs: highlights of data findings across states, usually focused on a particular indicator or group of indicators.
- Designed to spark your interest and raise awareness of things we find in the data.
- Released every 3 months.



Ways States Use NCI Data

- CMS Waiver Requirements
- Quality Assurance/Improve Services
- State by State Comparisons
- Assist with Community Transition
- Quality and DD Councils
- Reports to State Legislatures



NATIONAL CORE
INDICATORS



https://www.nationalcoreindicators.org/

The screenshot shows the homepage of the National Core Indicators (NCI) website. The browser address bar displays the URL <https://www.nationalcoreindicators.org>. The page features a teal header with the NCI logo and a navigation menu with links for HOME, ABOUT, NCI STATES, CHARTS, INDICATORS, RESOURCES, BLOG, NEWS, and CONTACT. A 'STATE LOGIN' button is visible in the top right. The main content area is titled 'Featured Core Indicators' and includes a descriptive paragraph about NCI, followed by three indicator cards: 'Feels Lonely', 'Person has Paid Job in the Community', and 'Allowed to Use Phone or Internet at Any Time'. Each card contains a bar chart, a brief description, and a 'READ MORE' button. At the bottom, there are sections for 'Participating NCI States' with a dropdown menu, 'NCI BLOG' with a 'Case Examples: NCI Data for Quality' link, and 'NCI News' with a recent article from July 2017.

For More Information

