

A festive background featuring colorful streamers in shades of pink, yellow, and purple, along with small, multi-colored confetti dots scattered across the white space.

# **National Core Indicators: Celebrating 20 Years**

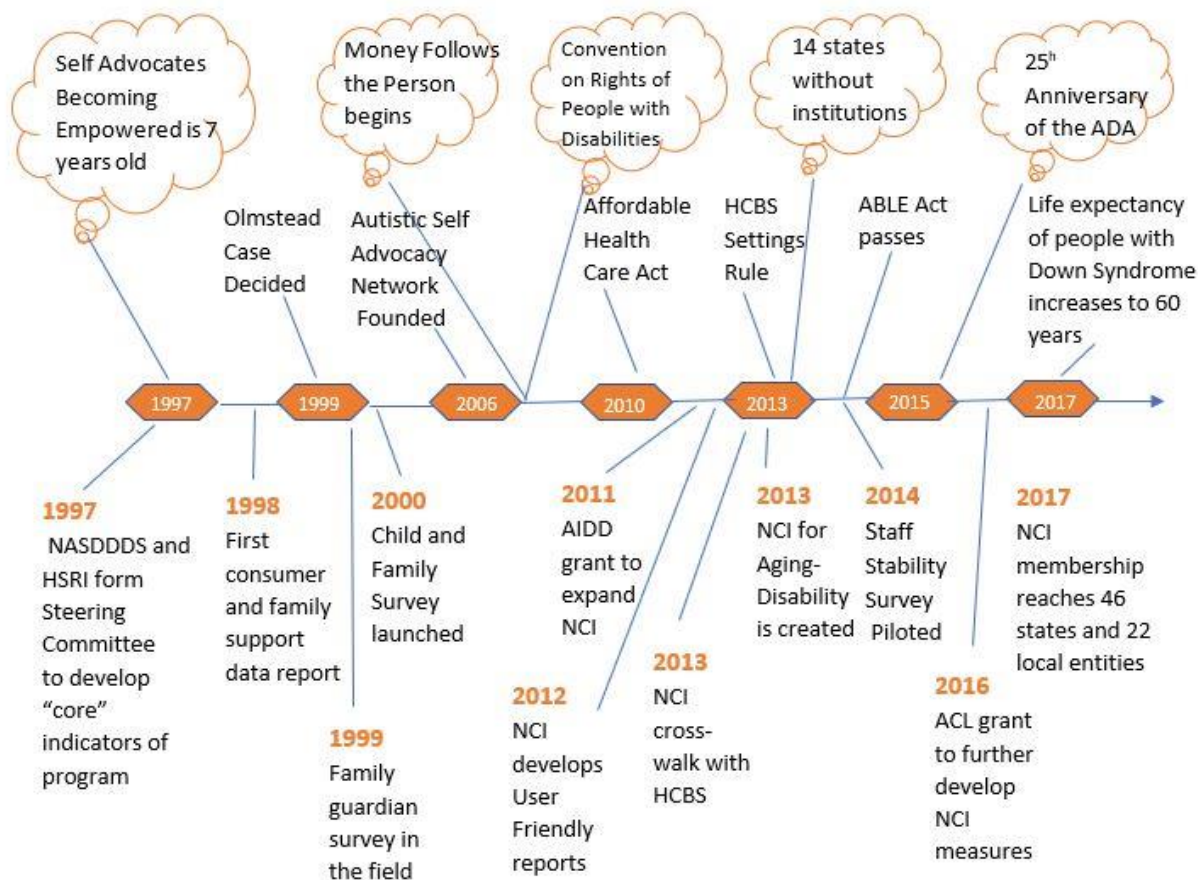
Valerie Bradley, President Emerita  
Human Services Research Institute  
NASDDDS Annual Meeting  
Alexandria, VA  
November 8, 2017



Human Services  
Research Institute

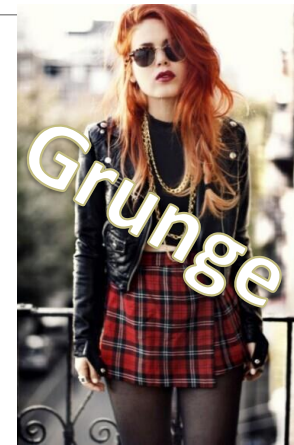
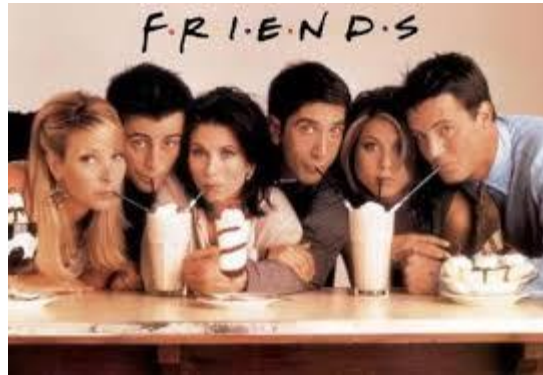
NASDDDS

# Sweep of 20 Years of History



# Memory Lane -- 1997

---



# Antecedents to NCI

---

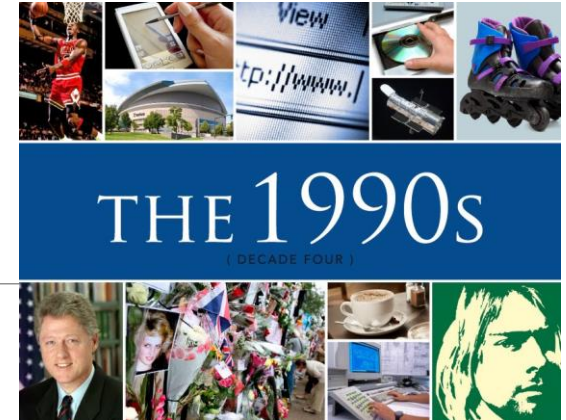
Growing interest in outcomes as a way to understand performance

Interest in transparency and the importance of making performance information public

Rising expectations about the ability of people with IDD to live real lives in the community

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 systems as the community system began to significantly outpace institutional services





# Who was There at the Beginning?



**Bob Gettings, Former  
Director of NASDDDS**



**Gary Smith, former  
policy director at  
NASDDDS**



**Valerie Bradley  
President Emerita  
of HSRI**



**John Ashbaugh,  
Former Vice  
President of HSRI**



**Sarah Taub  
Former NCI Project  
Director for HSRI**

# Early Stirrings

---

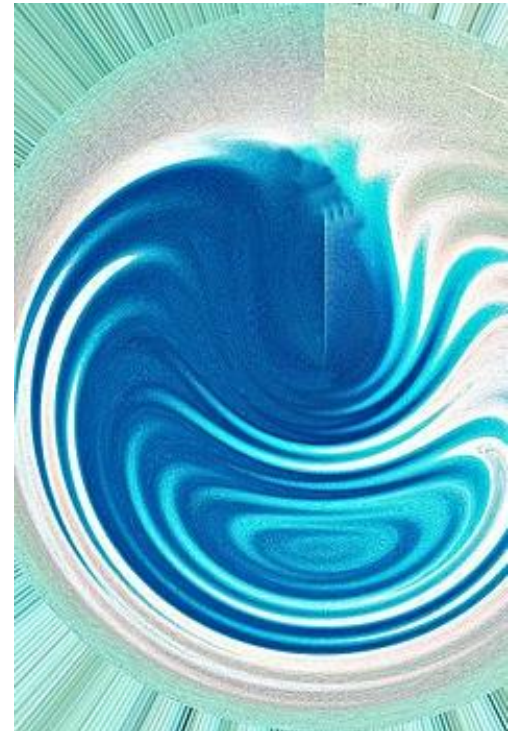
Formation of a Steering Committee  
made up of 13 state representative

Development of 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

Field test showed that the Adult Consumer Survey was reliable

Some questions were revised

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.



# Collaborations

---



Partnered with the University of Minnesota Institute on Community Integration for additional data analysis and publications

Partnered with University of Massachusetts Institute on Community Inclusion on employment data

Worked with individual states to develop special analyses

Worked with AUCD to ensure involvement of UCEDDs and graduate students

Received funding from the Administration on Developmental Disabilities

Partnered with National Association of States United for Aging and Disability to develop NCI-AD



# Enhancements to NCI Over the Past Two Decades

---

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

Developed an online data entry platform



# How Has NCI Stayed Dynamic and Reflective of Changes in the Field?

Increased the richness of the employment data and wage data in collaboration with UMass ICI

Expanded and enhanced the self-direction questions

Expanded background questions on health conditions

Re-examined questions on community inclusion to make them more person centered

Added questions in line with the requirements of HCBS Settings rule

Updated video training materials





How Have NCI Data Reflected Changes  
Over the Past 20 Years?



# How have things changed?

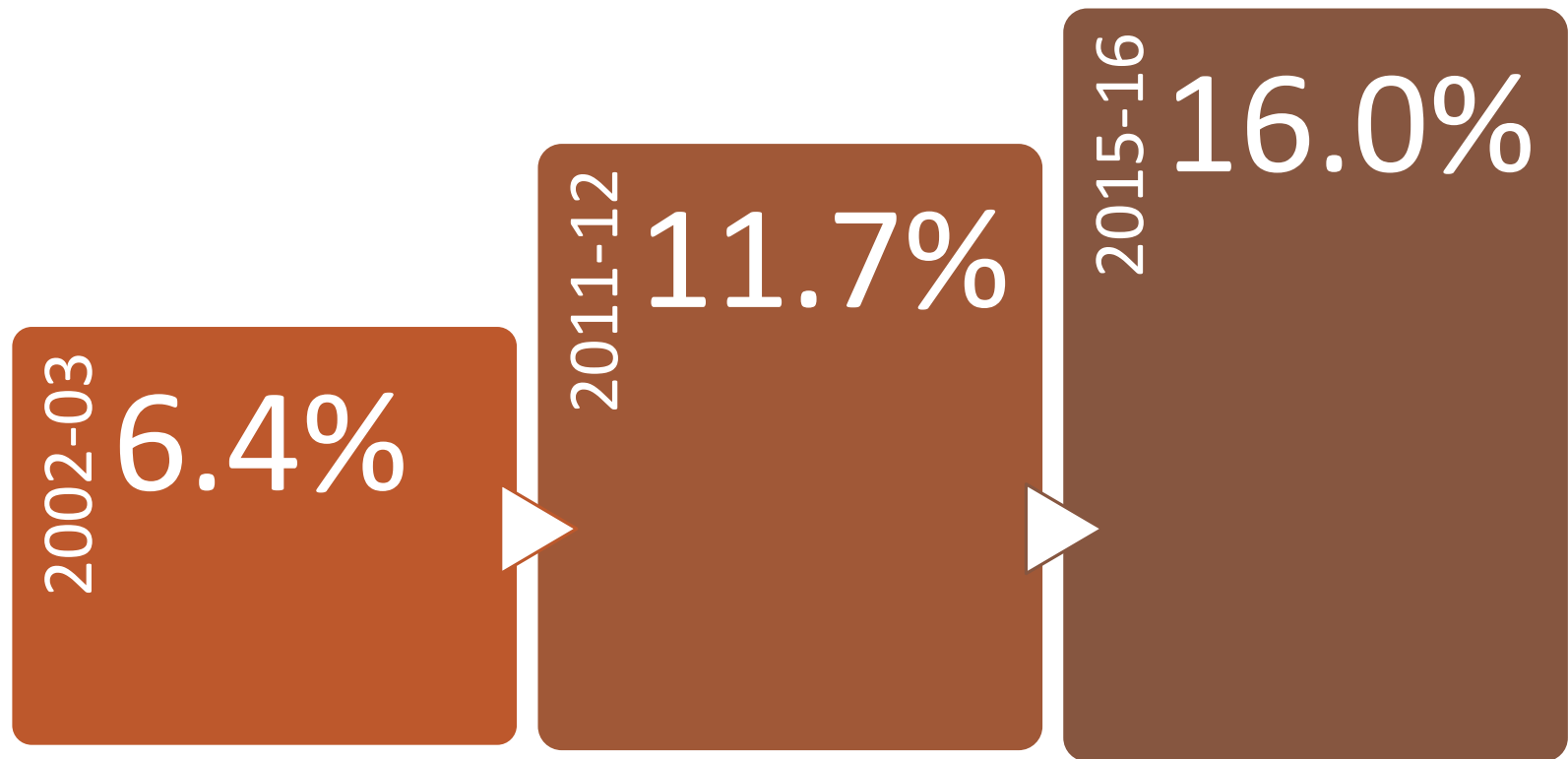
---

Looked at the NCI average for indicators of interest in three years:

- 2002-03 (N=9552) and
- 2011-12 (N=12236) and
- 2015-16 (N=17682)

# More People with an Autism Diagnosis

---





# Changes in Where People Live

(Response options  
have changed over  
time)



The percentage of people living in a parent/relative's home increased

2002-03: 29%

2011-12: 33%

There was a decrease in the percentages of people living in congregate settings (group homes, ICF, specialized institutional settings, etc.)

2002-03: 41%

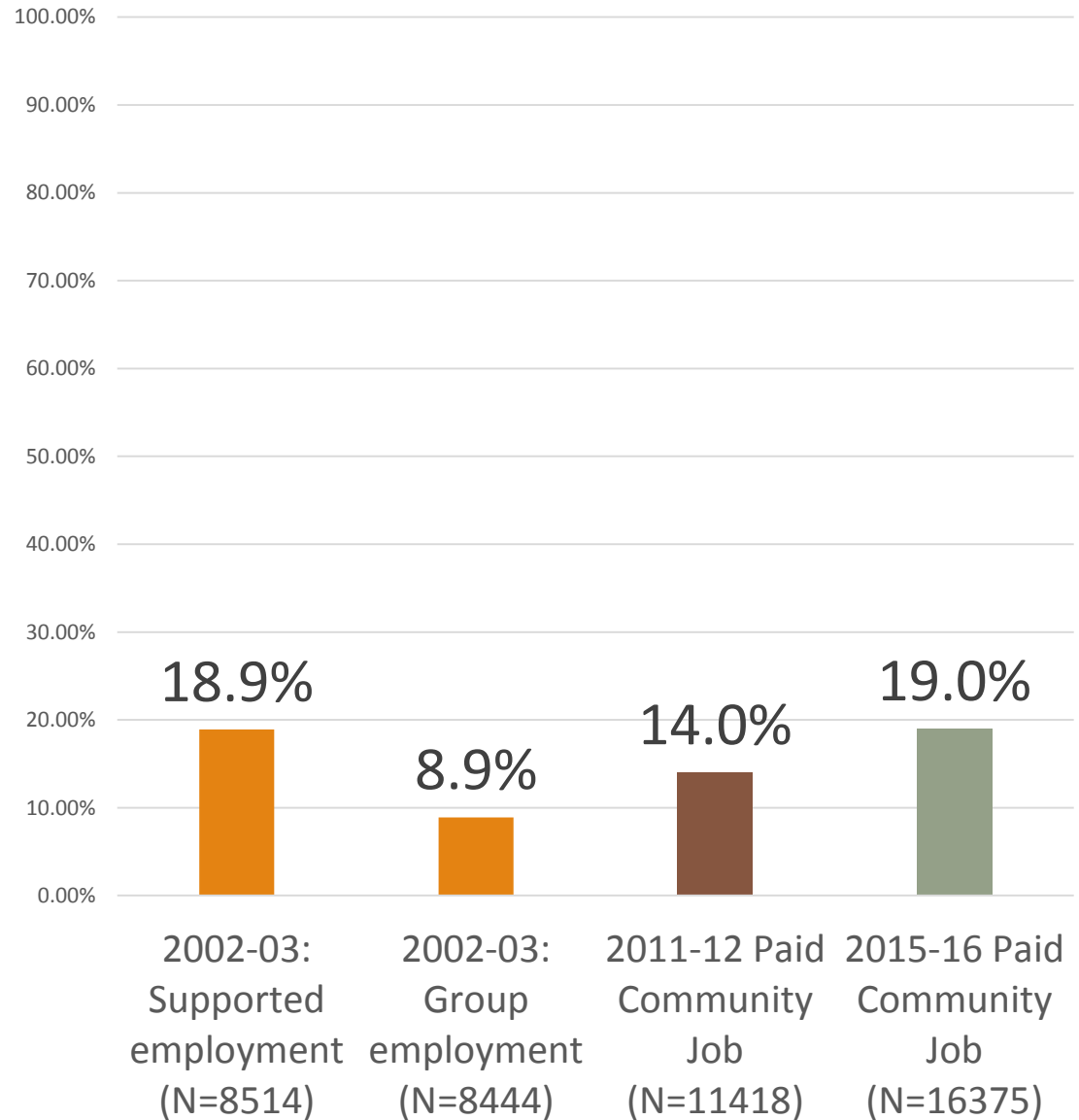
2015-16: 37%

There was a increase in the percentages of people living in independent homes/apartments institutional settings, etc.)

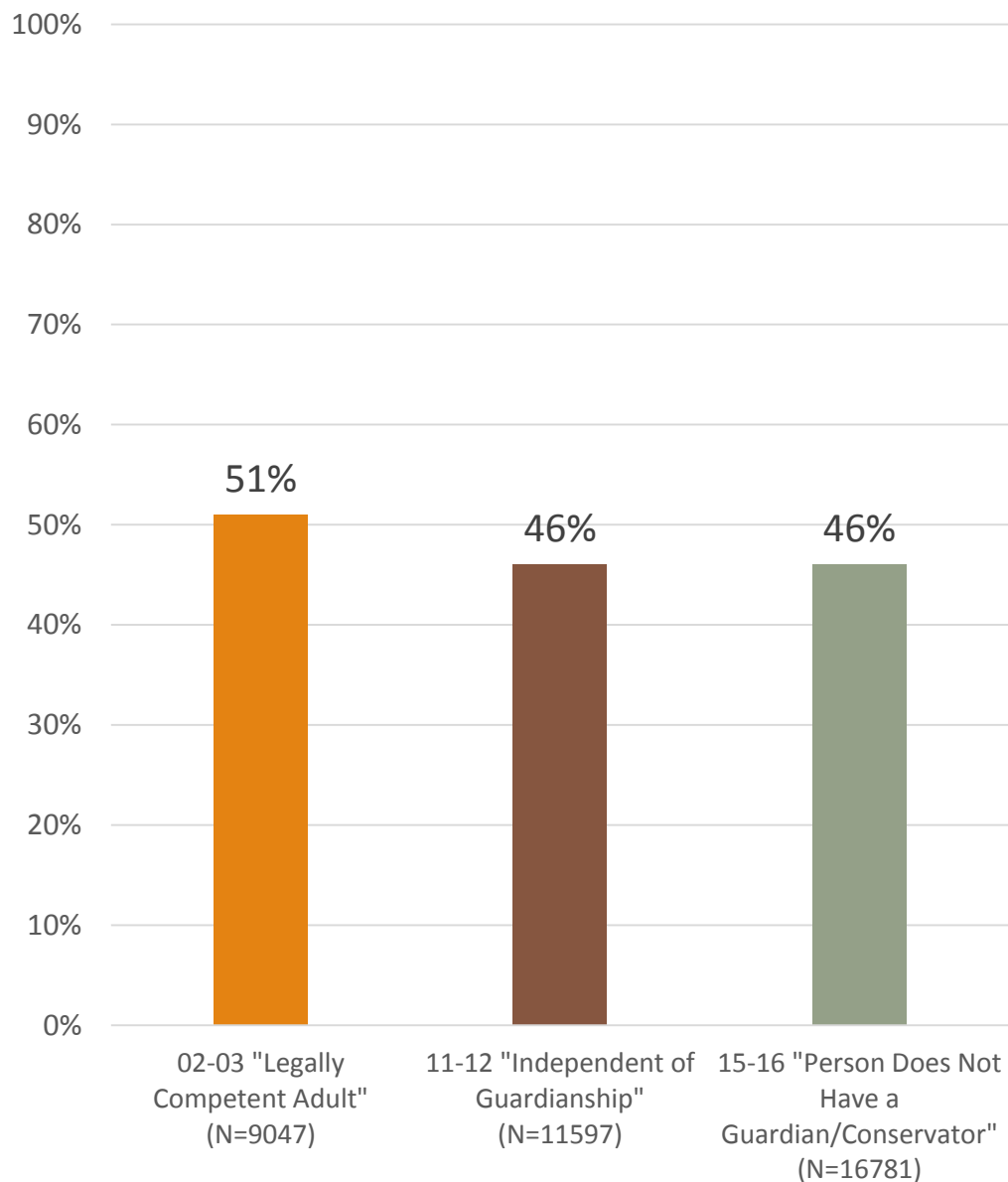
2002-03: 14%

2015-16: 20%

# Employment



# Legal Status





Has friends that  
are not staff or  
family

---

2002-03:  
71.5%

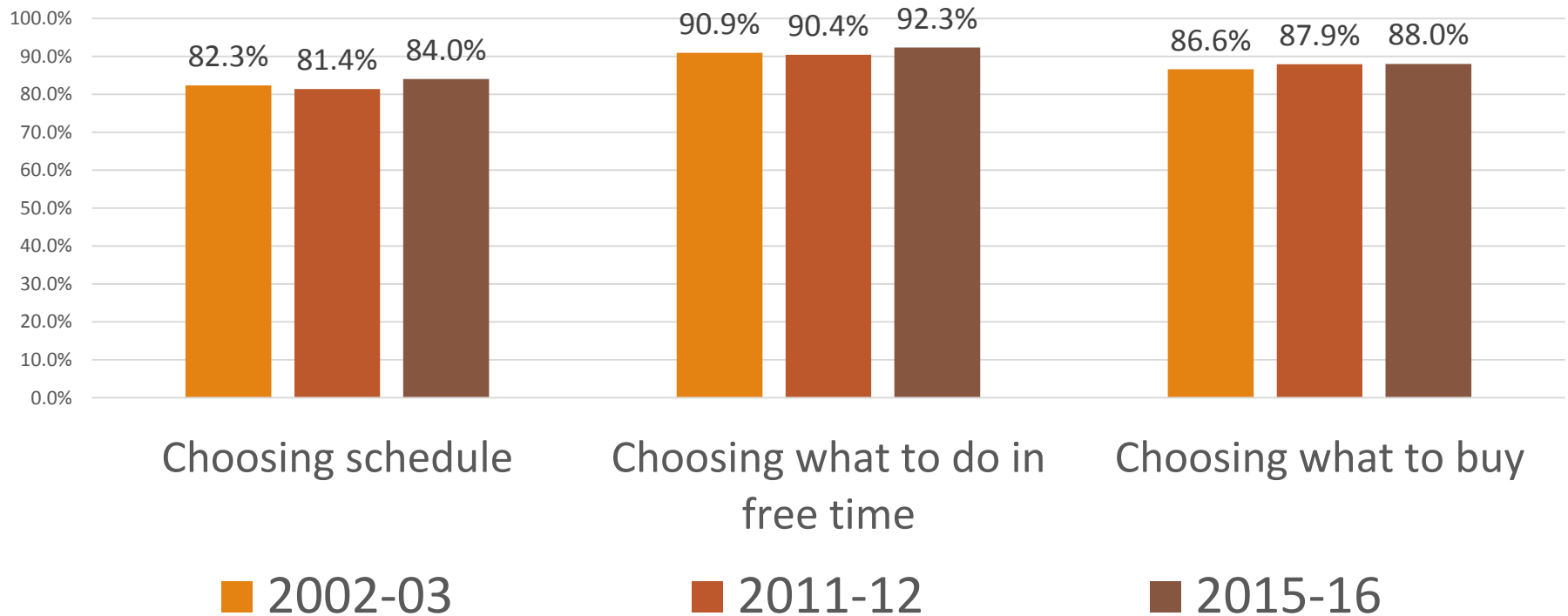
2011-12:  
70.2%

2015-16:  
77.3%

# Choice



Person had at least some input in the following choices:

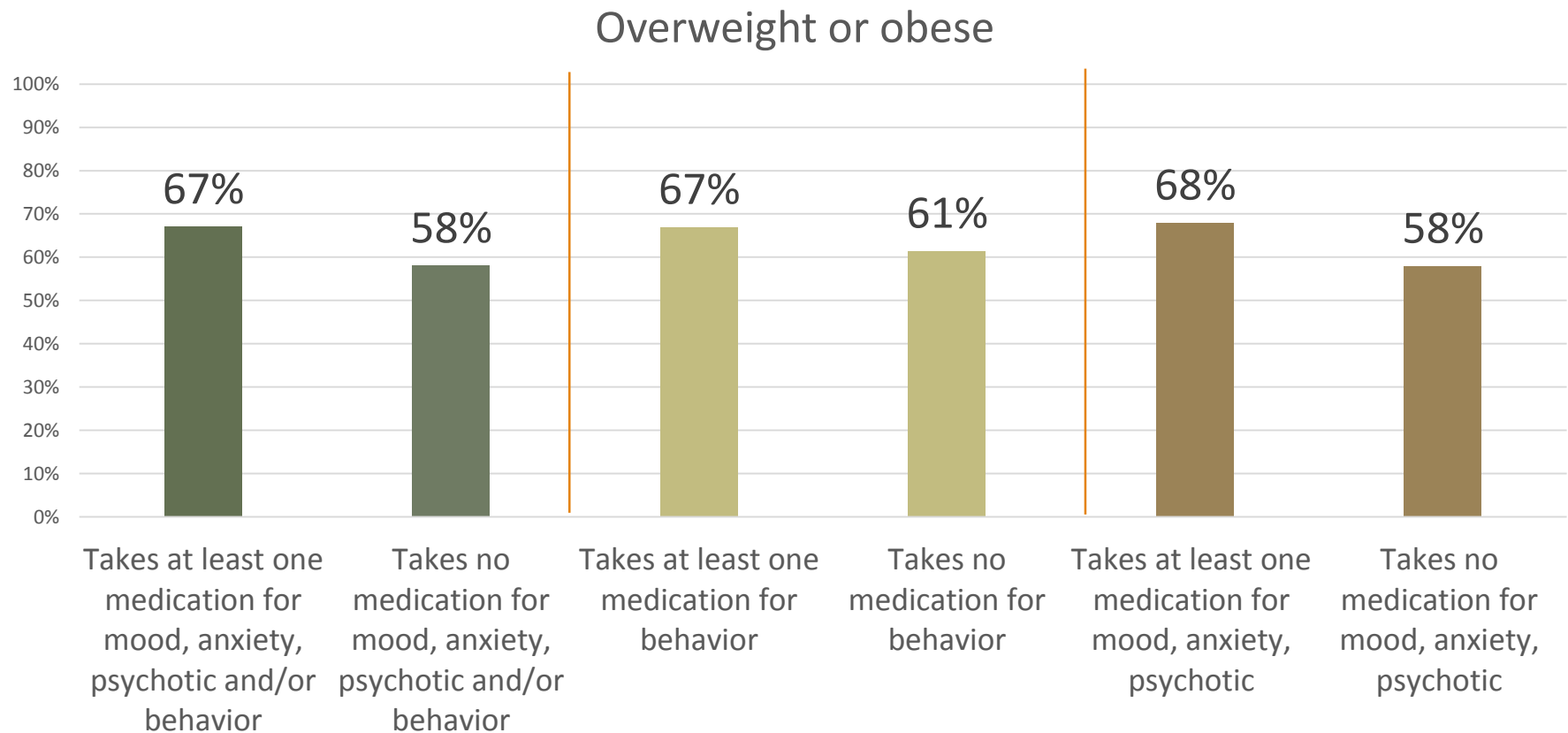




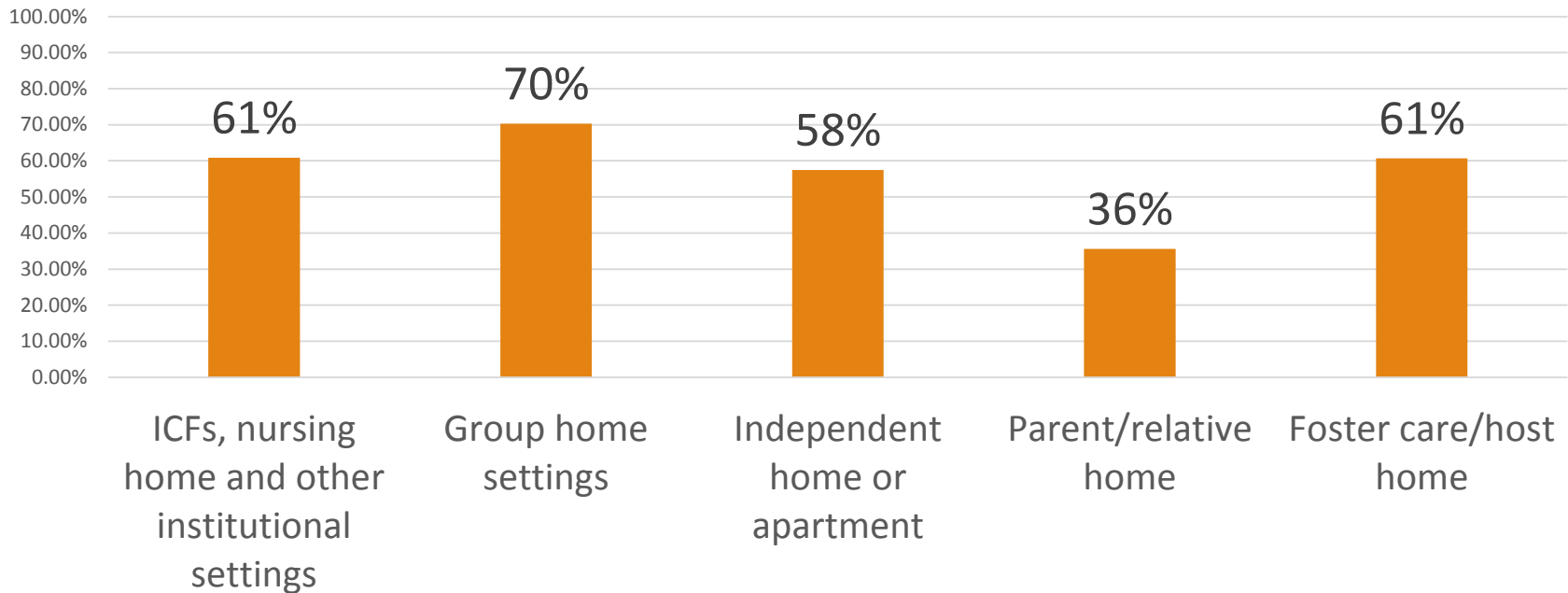
# Issues that NCI Data Have Shed Light On



# Those taking medication were significantly more likely to be overweight or obese



## Percentage taking at least one medication for mood, anxiety, psychotic and/or behavior



# Medication by residence type

# Data Brief: Friendship and Life Outcomes

**Expanded Friendships:** Has friends who are not staff/family

**Limited friendships:** No friends, or friends are only staff and/or family

## **Employment:**

Individuals who had expanded friendships were **more likely to be employed in a paid community job**

## **Rights and Privacy:**

Those who had expanded friendships reported **having more privacy**; they also reported **having their rights respected** at greater rates.

## **Community Inclusion**

Those with expanded friendships were more likely to have **gone into the community to take part in specific activities**; they also reported participating in these activities with greater frequency.

People with ASD were less likely to be independent of guardianship

People with ASD were less likely than those without ASD to say they had friends who weren't family or staff

People with ASD were less likely to report having had at least some input in critical life choices such as choosing staff, daily schedule, free-time, etc.

People with ASD were significantly more likely to live in the family home, and significantly less likely to live in their own home and apartment

## Article: Outcomes for those with ASD

Hiersteiner, D., Bradley, V., Ne'eman, A., Bershadsky, J. & Bonardi, A. (2017) Putting the research in context: The life experience and outcomes of adults on the autism spectrum receiving services in 29 states. *Inclusion* 5(1) 45-59





How Has NCI Influenced State Policy Changes?

# How States Use NCI Data

## **New York**

Publishes comparison data against other states

Targeted campaigns to decrease obesity rates

## **Ohio Council of Governments**

Tracks person centered practices and changed the terminology of their planning process

## **Kentucky**

Issues formal report on service quality and community participation

## **Massachusetts**

Tracks and acts on health and wellness and safety data

# Use of NCI with Federal Regulations



A Collaboration of  
the National Association of State Directors of  
Developmental Disabilities Services  
and Human Services Research Institute

## **NCI Performance Indicators: Evidence for New HCBS Requirements and Revised HCBS Assurances**

### **Practical Tools for States**

Prepared by Elizabeth Pell, MSW, LICSW  
Human Services Research Institute

May 29, 2014

National Core Indicators Publication    [www.nationalcoreindicators.org](http://www.nationalcoreindicators.org)

# NCI: Strengthening Service Delivery and Quality System-Wide

QUALITY MATTERS

QM

Providing NCI survey findings to state and regional quality councils for review, analysis and feedback

Identifying quality concerns and prioritizing service improvement activities

Comparing the state's performance against that of other states

Targeting areas for remediation and improvement at the state and system levels in line with CMS requirements

## How Have States Used NCI Data?

- Benchmarking system performance
- Compare system performance with other states and to NCI average
- QA
- CMS assurances/HCBS transition plans
- Advocacy



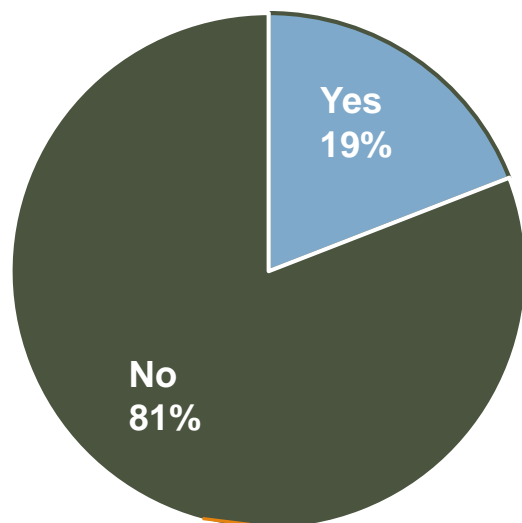


What Are  
Some  
Recent  
Data  
Highlights?

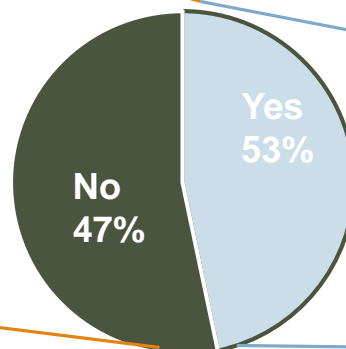


# 2015-2016 NCI Adult Survey

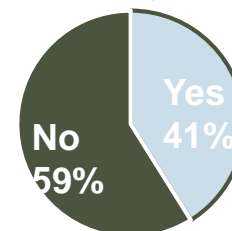
Has a Job (n=16,375)



Would like a Job  
(n=6,550)



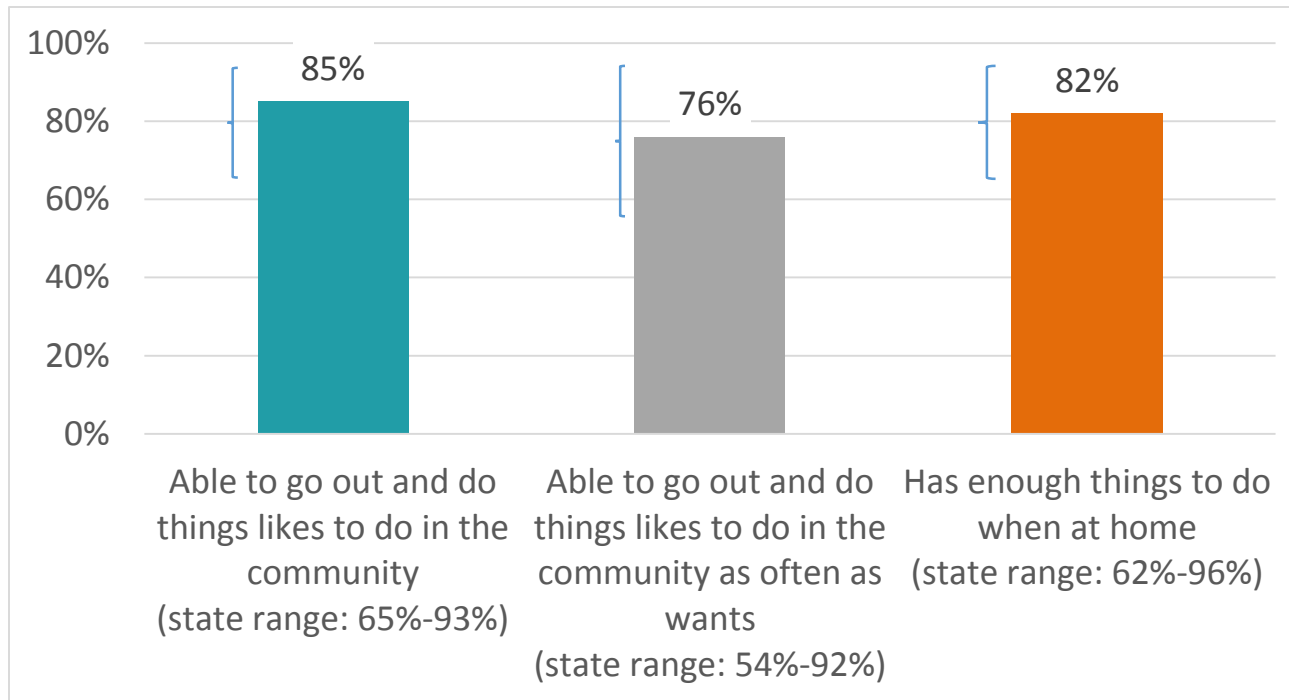
Employment goal  
in Plan (n=2,808)



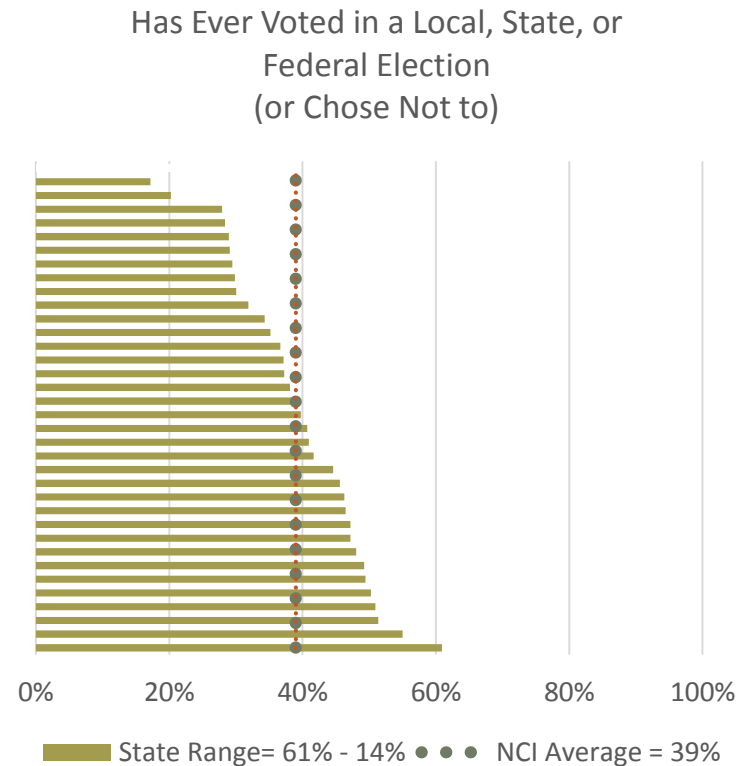
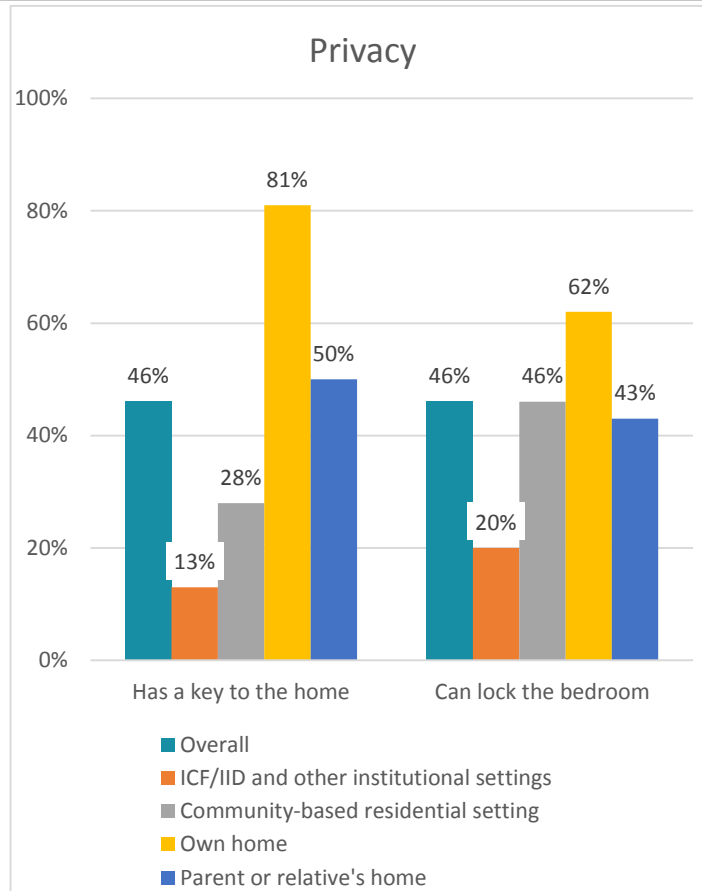
**24%** took classes, training, or did something to get a job or get a better job

# Community Participation and Leisure

---



# Privacy and Rights





Where Do We Go From Here and What are the Challenges?

# At the Forefront

---

Secure NQF certifications for some of the NCI Indicators

Continue to give states value for membership in NCI

Think through how NCI can work within a managed care context

Continue to ensure the validity and reliability of the data

Maximize the synergy with NCI-AD

... And Now a Celebratory Video

---

