



How State ID/DD Systems Can Use National Core Indicators to Assess Congruence with New CMS HCBS Settings Requirements

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What Will We Cover?

- History and Purpose of NCI
- Data collection and outcome indicators
- Selected findings from the consumer and family surveys
- How states have used NCI data
 - A crosswalk between NCI and HCBS
 - Quality assurance in the states



National Core Indicators Background

- Launched in 1997 in 13 participating states
- Collaboration between NASDDDS, HSRI and 41 participating state DD agencies (including DC) and 22 sub-state regional entities.
- Current data base includes approximately 20,000 individuals receiving services and supports
- NCI tools assess performance in several areas, including: employment, community inclusion, choice, rights, and health and safety



NCI MEASURES OFFER A UNIQUE VIEW

- Person-centered
- Individual characteristics of people receiving services
- The locations where people live
- The activities they engage in during the day including whether they are working
- The nature of their experiences with the supports that they receive (e.g., with case managers, ability to make choices, self-direction)
- The context of their lives – friends, community involvement, safety
- Health and well-being, access to healthcare



NCI System Performance Measures

Individual Outcomes



- Employment
- Community Participation
- Choice & Decision making
- Personal Relationships

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



National Core Indicators Design

Valid

- Measure what is intended to be measured

Reliable

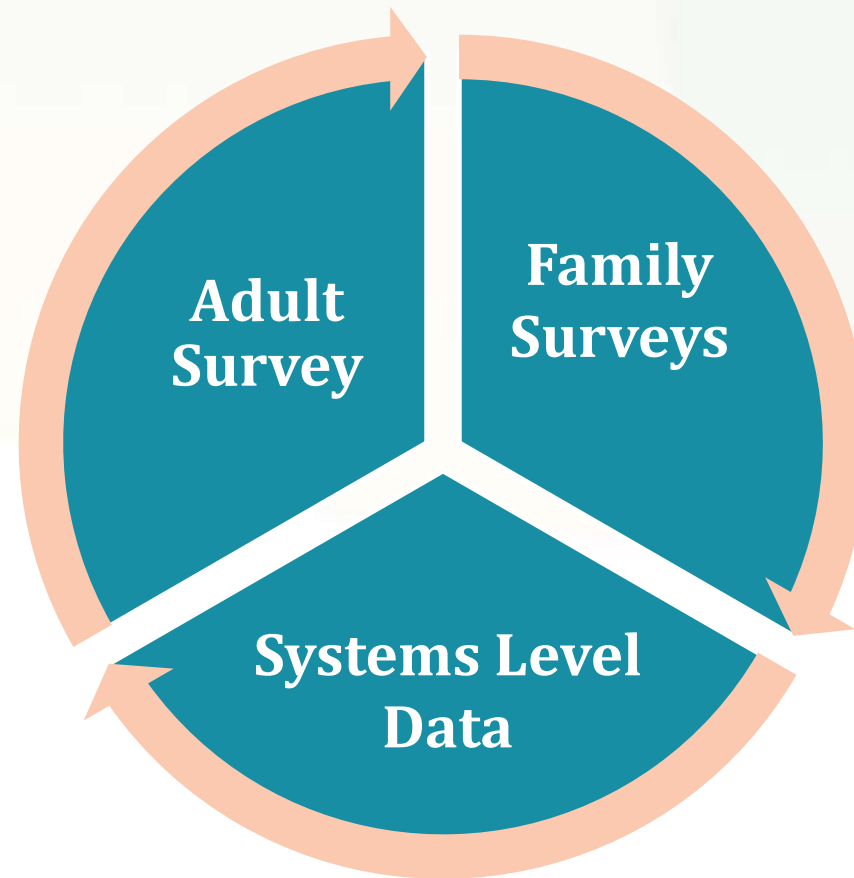
- Provide consistent results over time and interviewers

Risk Adjusted

- Provides multiple state comparisons



What are the Data Sources?

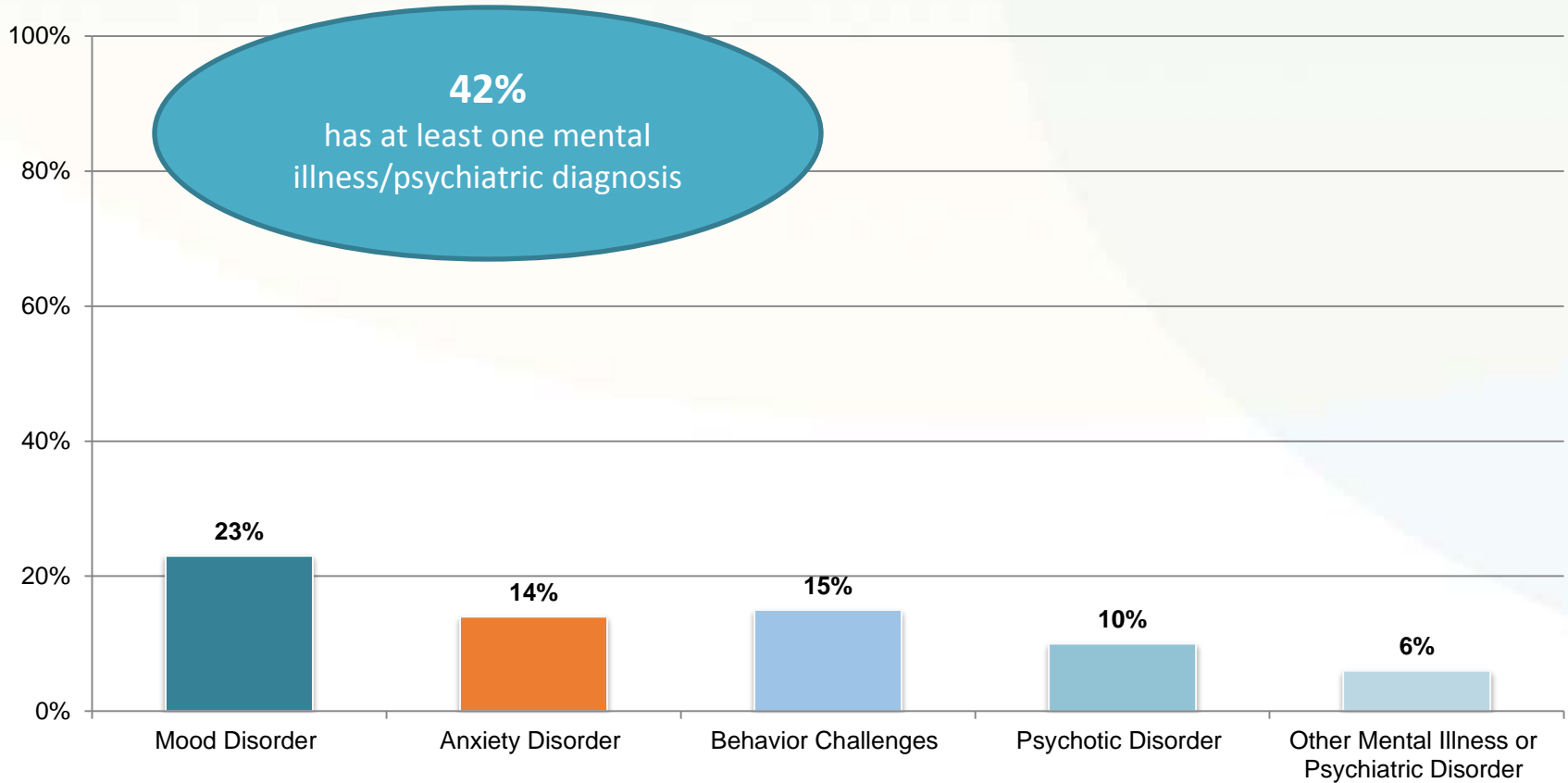


Use of Data to Identify Specific Policy Issues

Review of Selected Findings
from the 2012-2013
Adult Consumer Survey

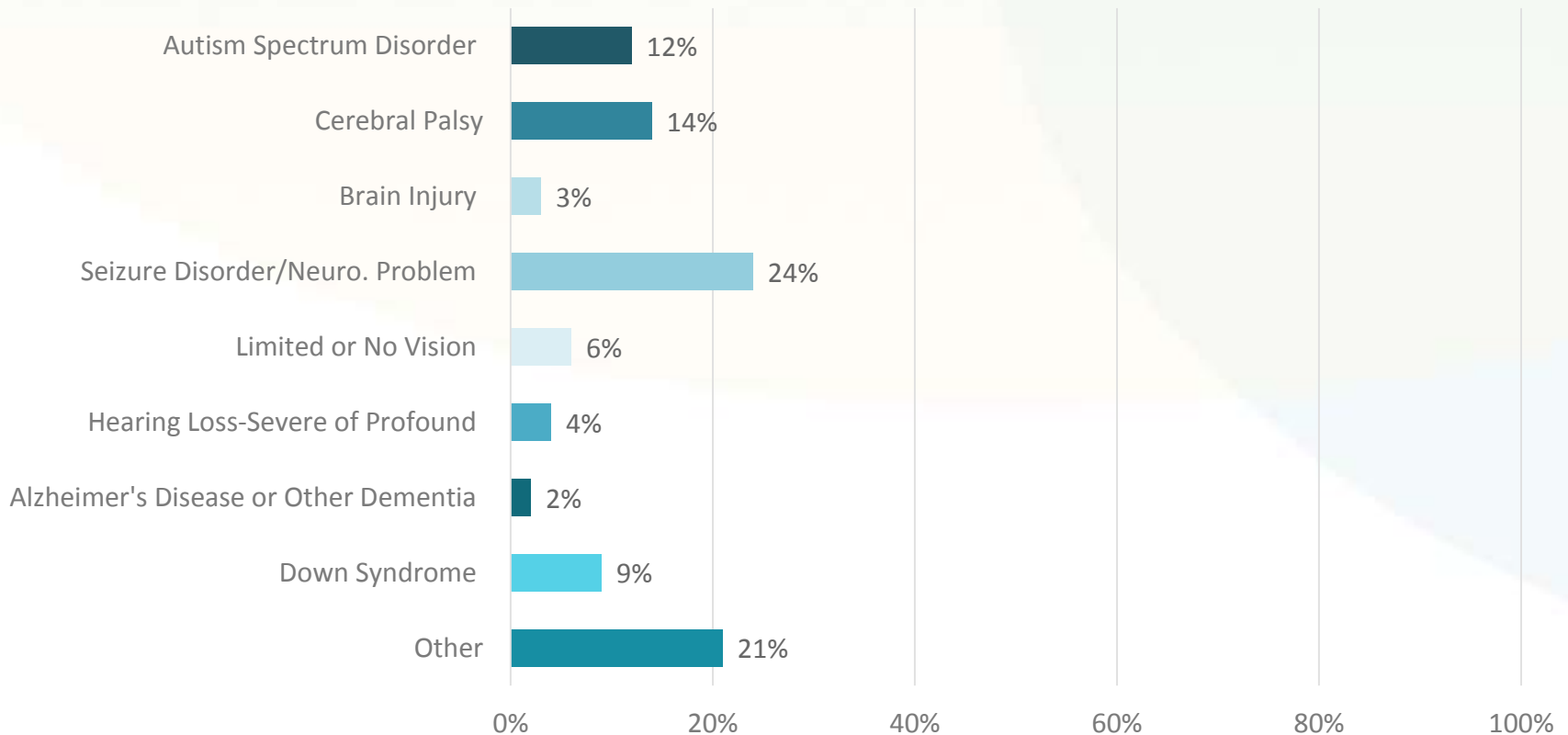
Diagnoses Other Than ID/DD

Mood Disorder, Anxiety Disorder, Behavior Challenges, Psychotic Disorder, and Other Mental Illness



Diagnoses Other Than ID/DD

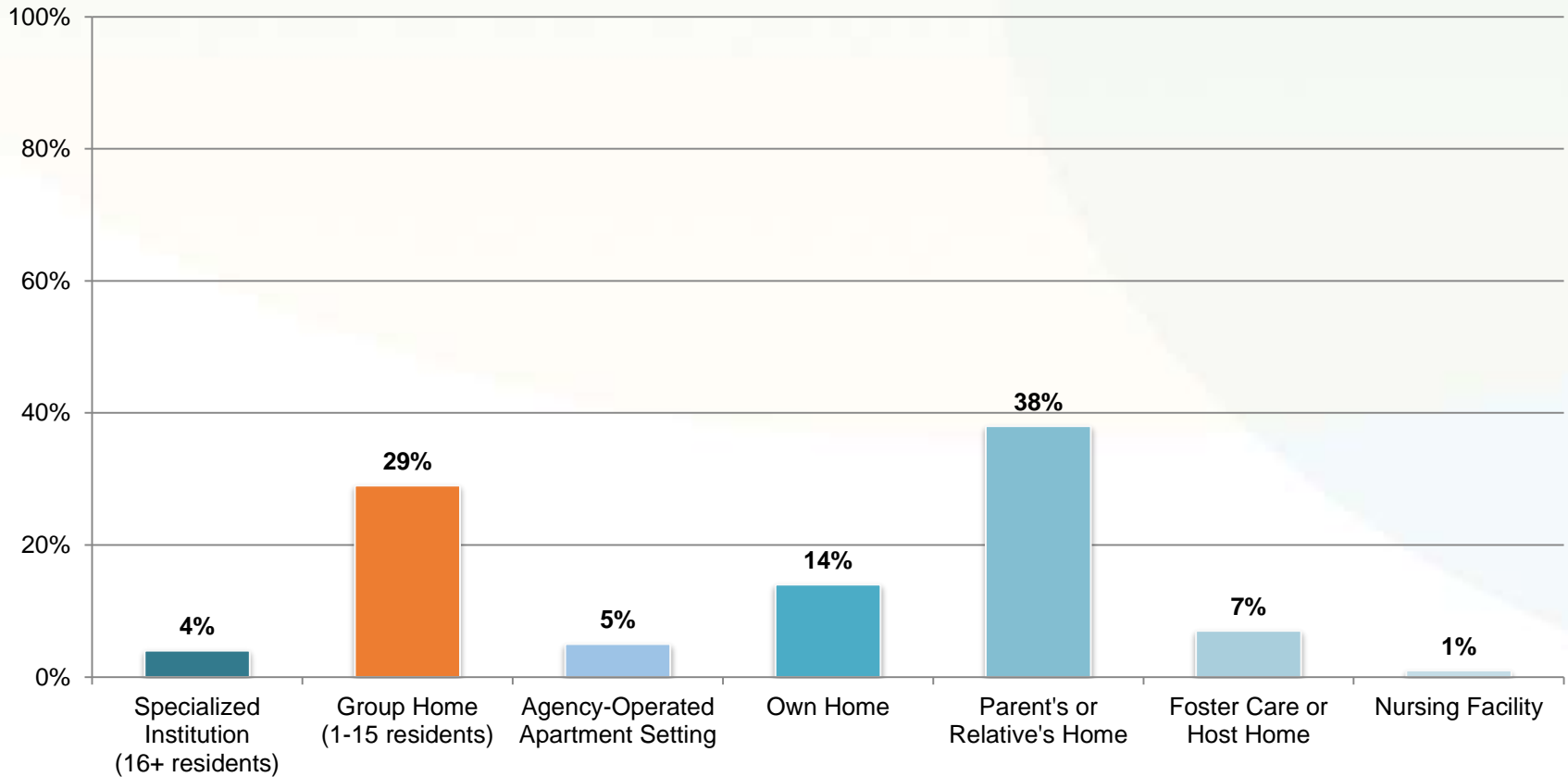
Other Diagnoses





Where People Live

Residence

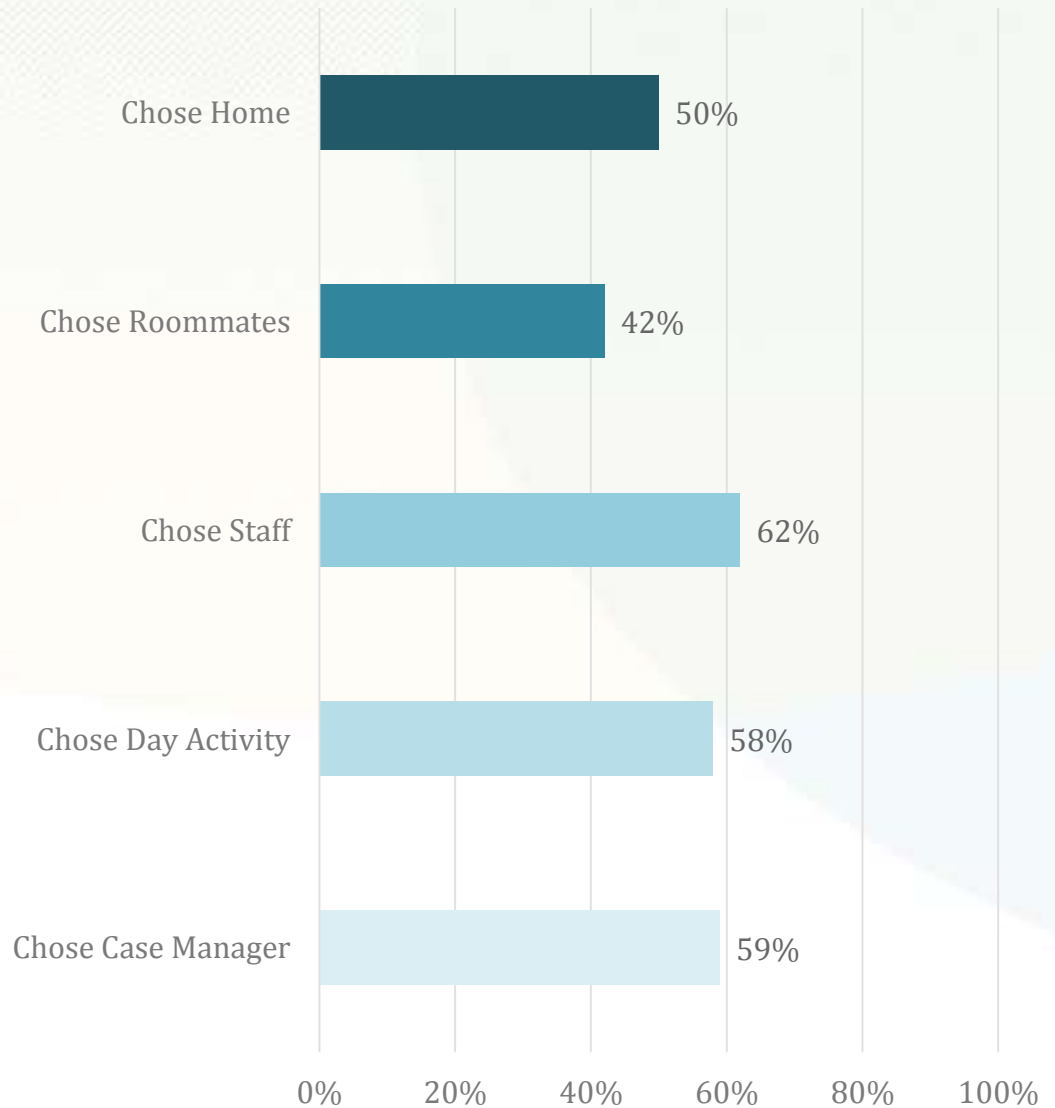


Choice and Decision-Making

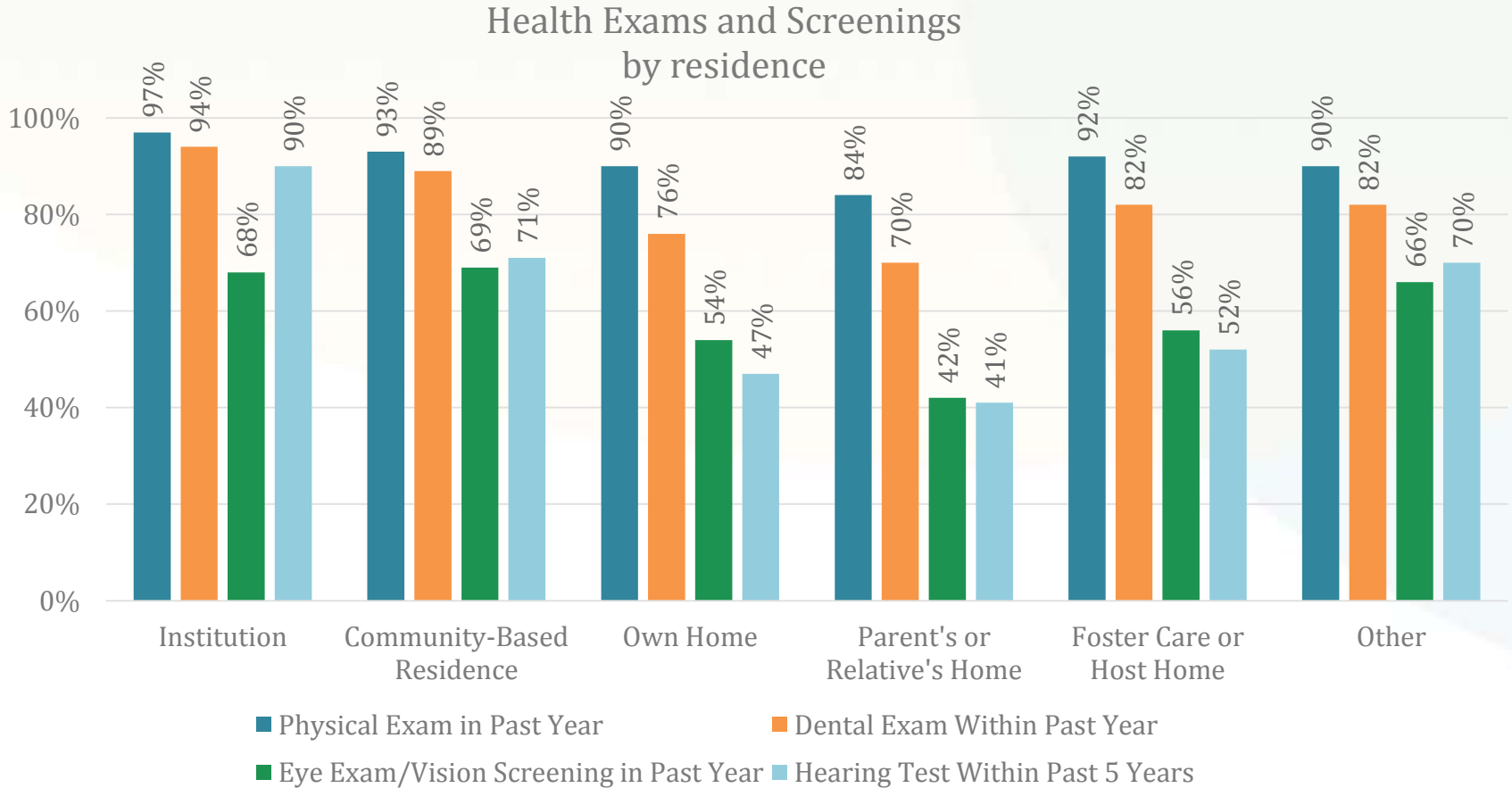
Everyday Choice:

- 82% daily schedule
- 91% free time
- 87% what to buy

Life Decisions



Basic Exams & Screenings



Medications and Mental Illness

- **48%** of people who need support for behavior issues take meds for behavior problems
- **7%** of people who do not need support for behavior issues take meds for behavior problems
- **86%** of people with MI or a psychiatric disorder take meds for mood, anxiety, or psychotic disorders
- BUT **52%** of people *not diagnosed* with MI or a psychiatric disorder *also* take meds for behavior, mood, anxiety, or psychotic disorders



Psychotropic medication use increases health complications

- Weight gain
- Abnormal glucose metabolism (diabetes)
- Cardiovascular disturbances
- Oral health issues
- Extra pyramidal symptoms, TD.

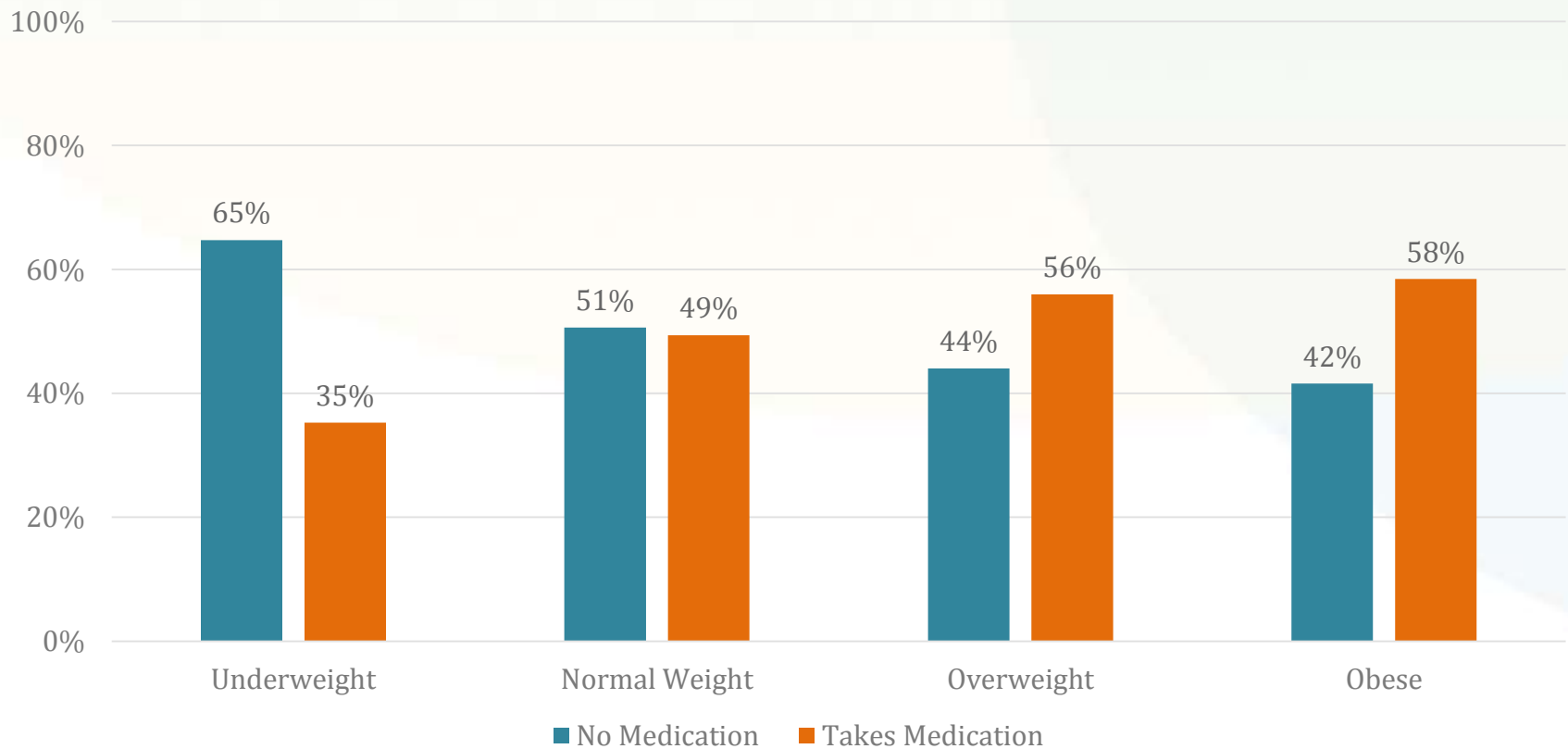
Lunsky & Elserafi (2011) Research in Developmental Disabilities



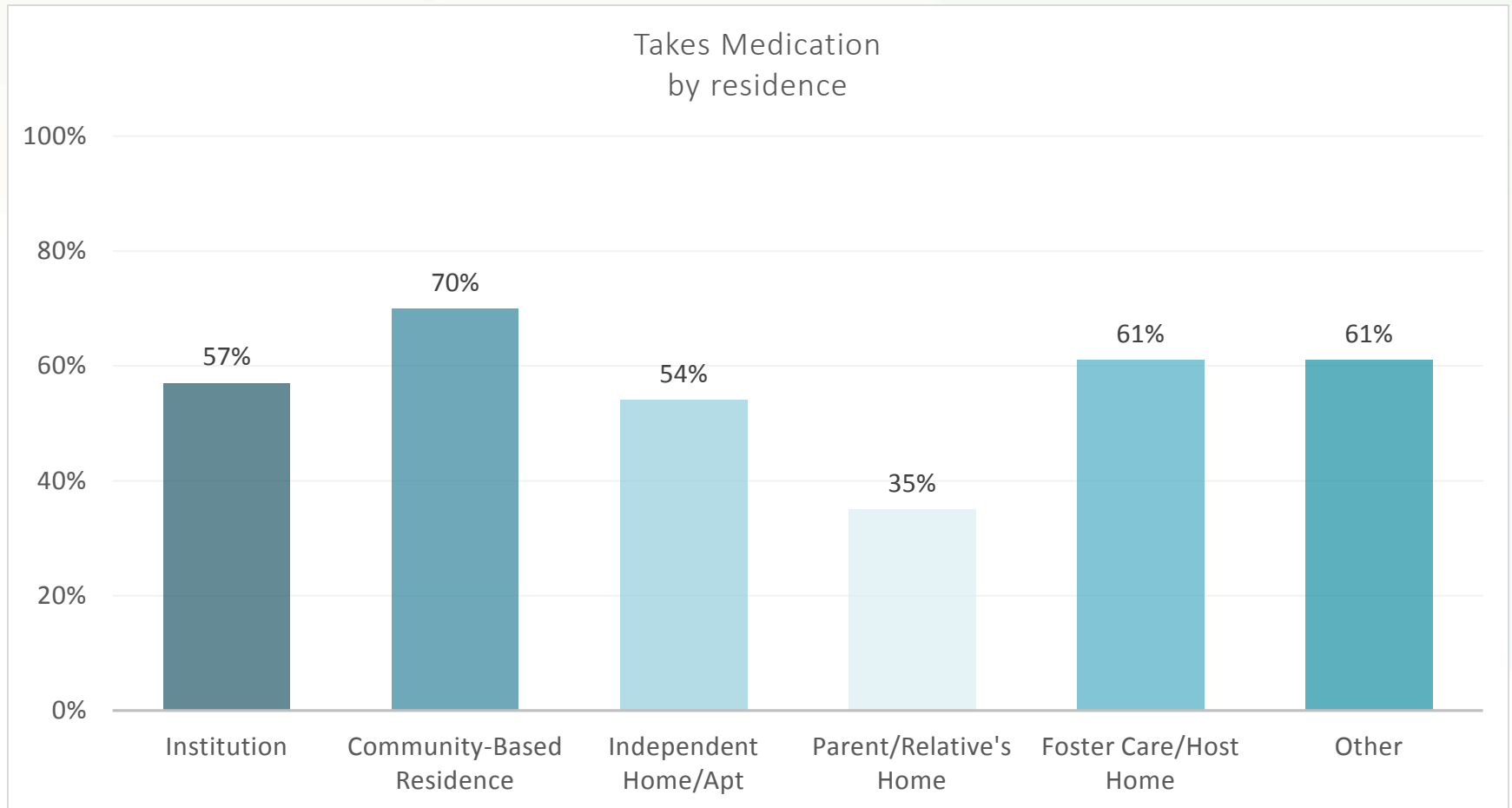
Use of Psychotropic Medications and Obesity



BMI and Medication



Takes At Least One Medication by Living Arrangement



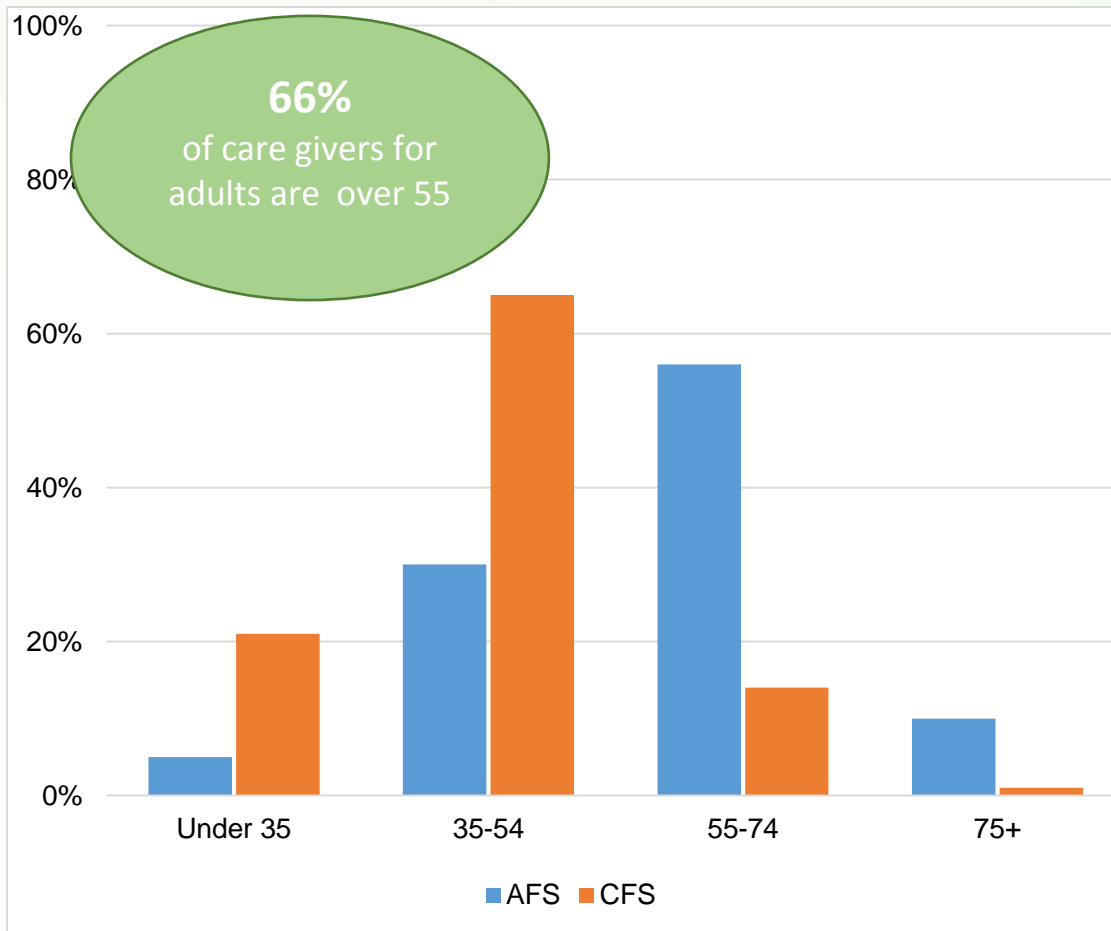
Families with Adults with ID/DD Living at Home

Selected Findings 2012-13

Adult and Child Family

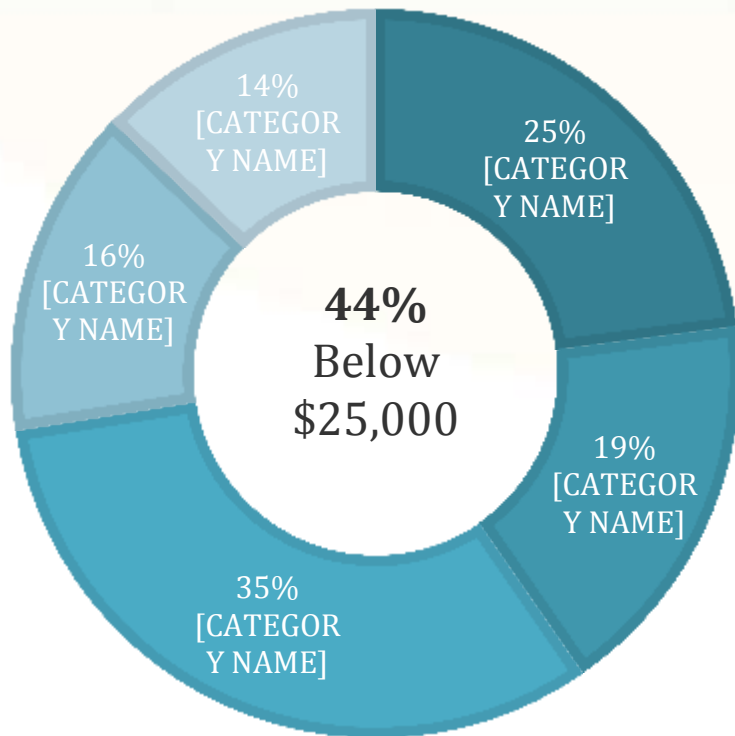
Surveys

Age of Care Givers

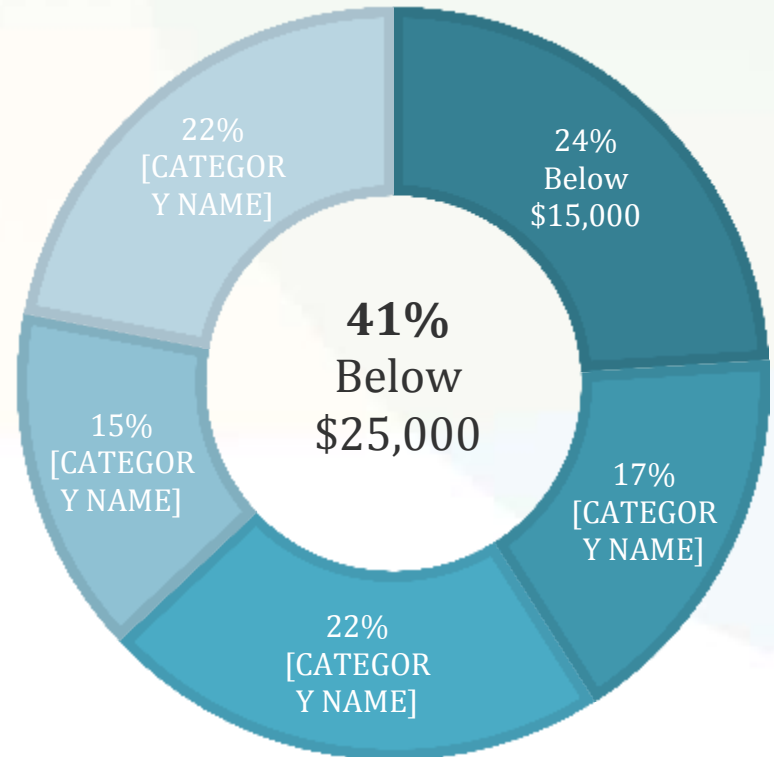


Family Income

AFS



CFS



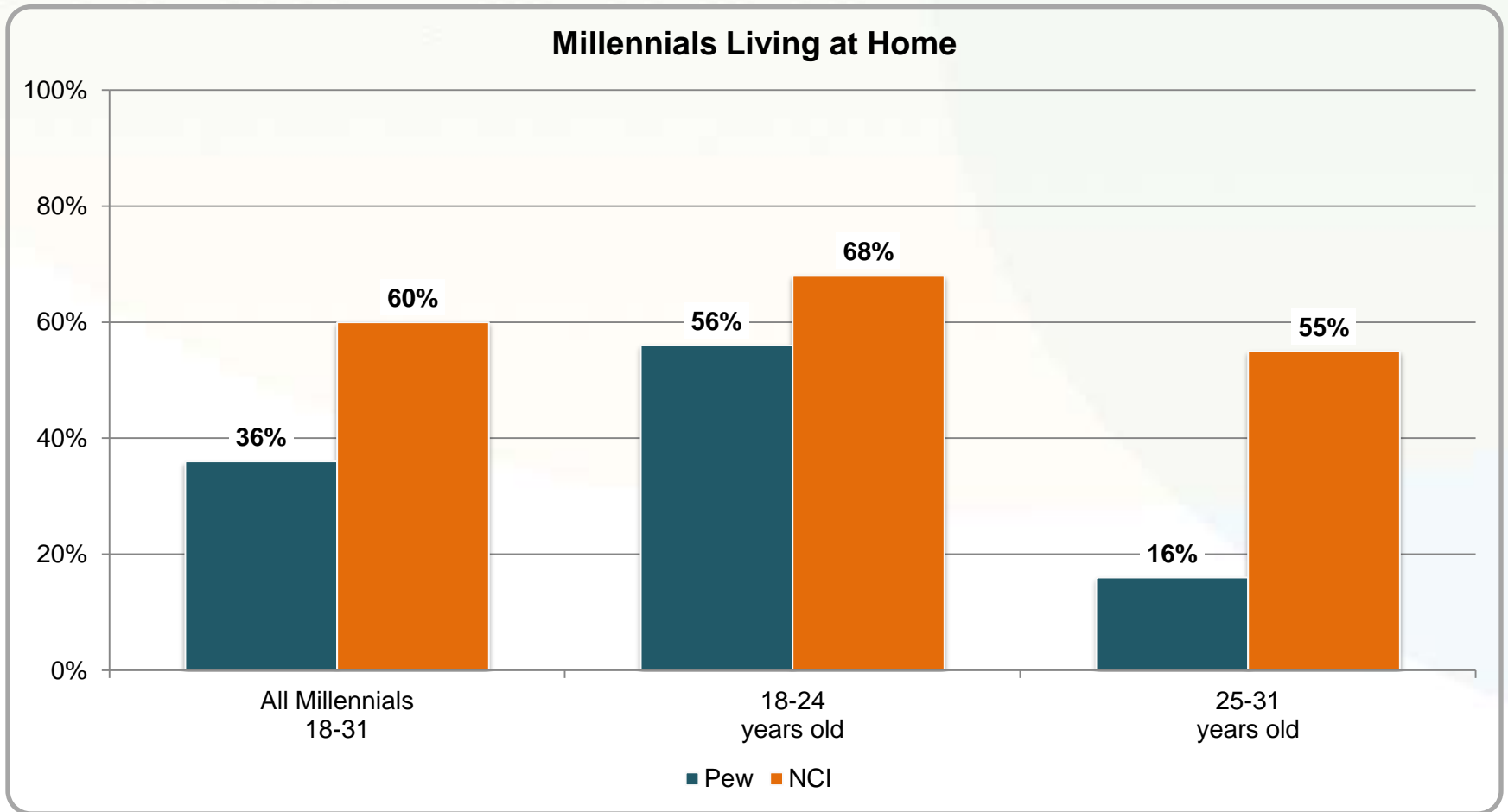
2012 HHS Poverty Guidelines for a Family of Four: \$23,050



NCI Comparisons

What Does NCI Tell Us About the Lives of People with ID/DD Compared to the General Population

Millennials



Pew Research data:

<http://www.pewsocialtrends.org/2013/08/01/a-rising-share-of-young-adults-live-in-their-parents-home/>





**NATIONAL CORE
INDICATORS**
NASDDDS & HSRI



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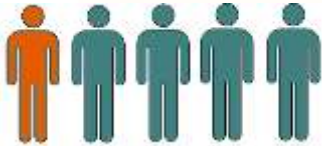


**NATIONAL CORE
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NASDDDS & HSRI

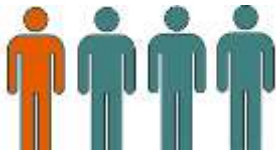
Medication Use

Medco Health Solutions 2010 data

- 1 in 5 took at least 1 psychiatric medication in 2010

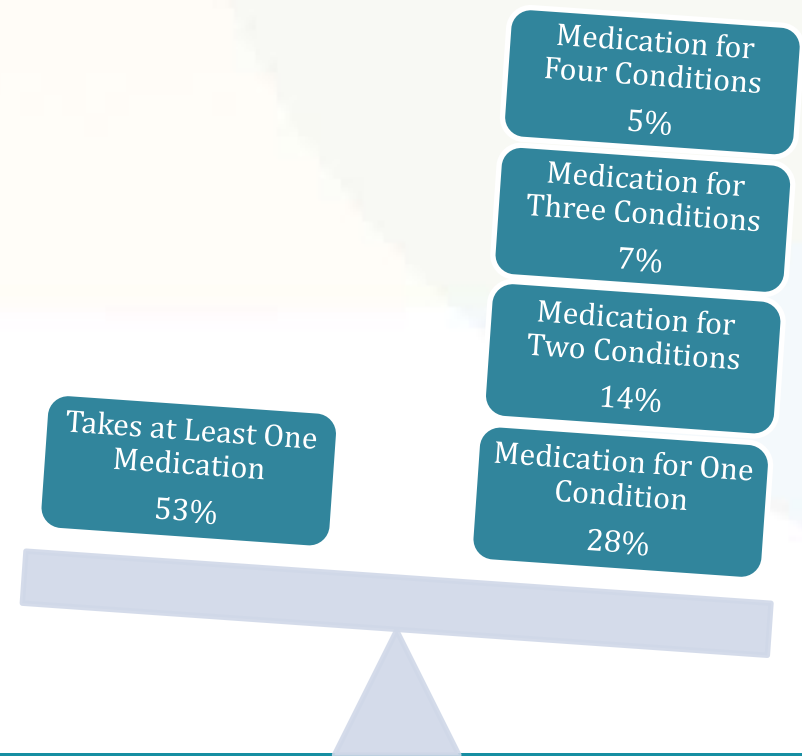


- 1 in 4 women took at least 1 psychiatric medication in 2010



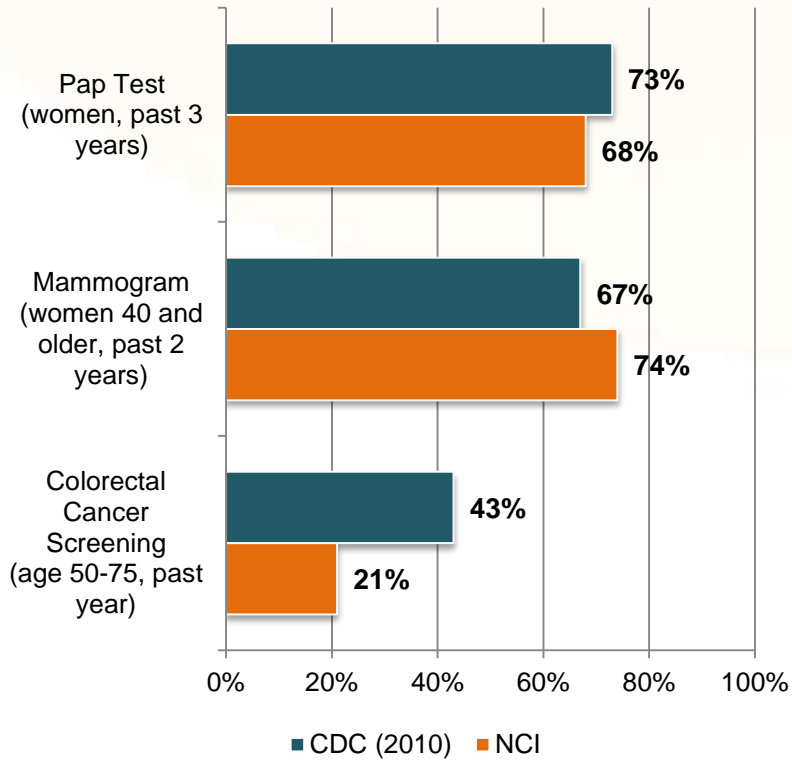
Medco Source:
<http://apps.who.int/medicinedocs/documents/s19032en/s19032en.pdf>

CA Medication use for mood, behavior, anxiety, and/or psychotic disorder

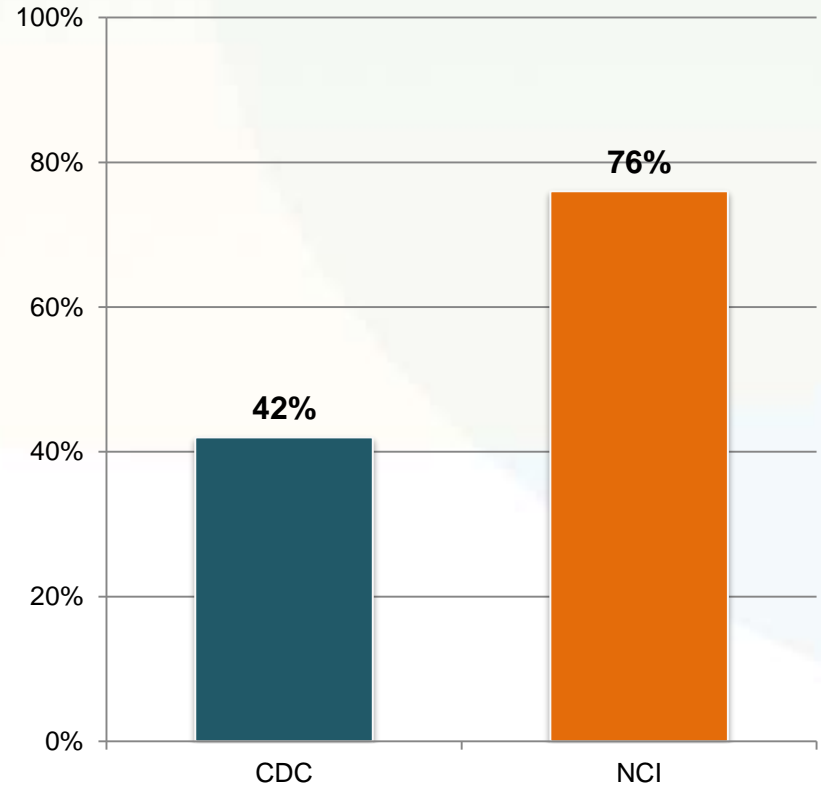


Flu Vaccination

Preventive Screenings

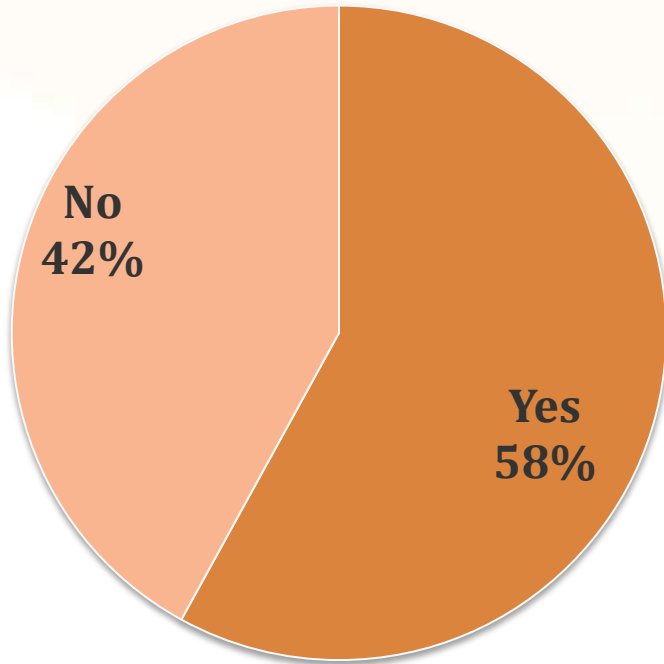


Flu Vaccination

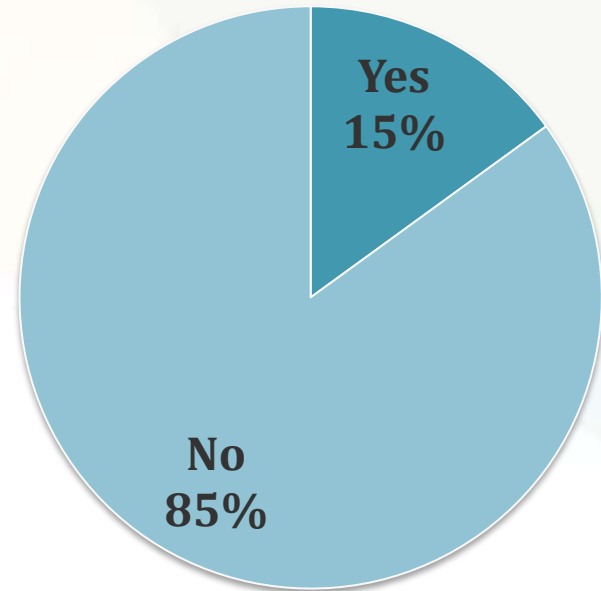


Employment

Bureau of Labor Statistics
Employed, age 16 and older



NCI
Collected from the Background
Information Section of the Adult
Consumer Survey

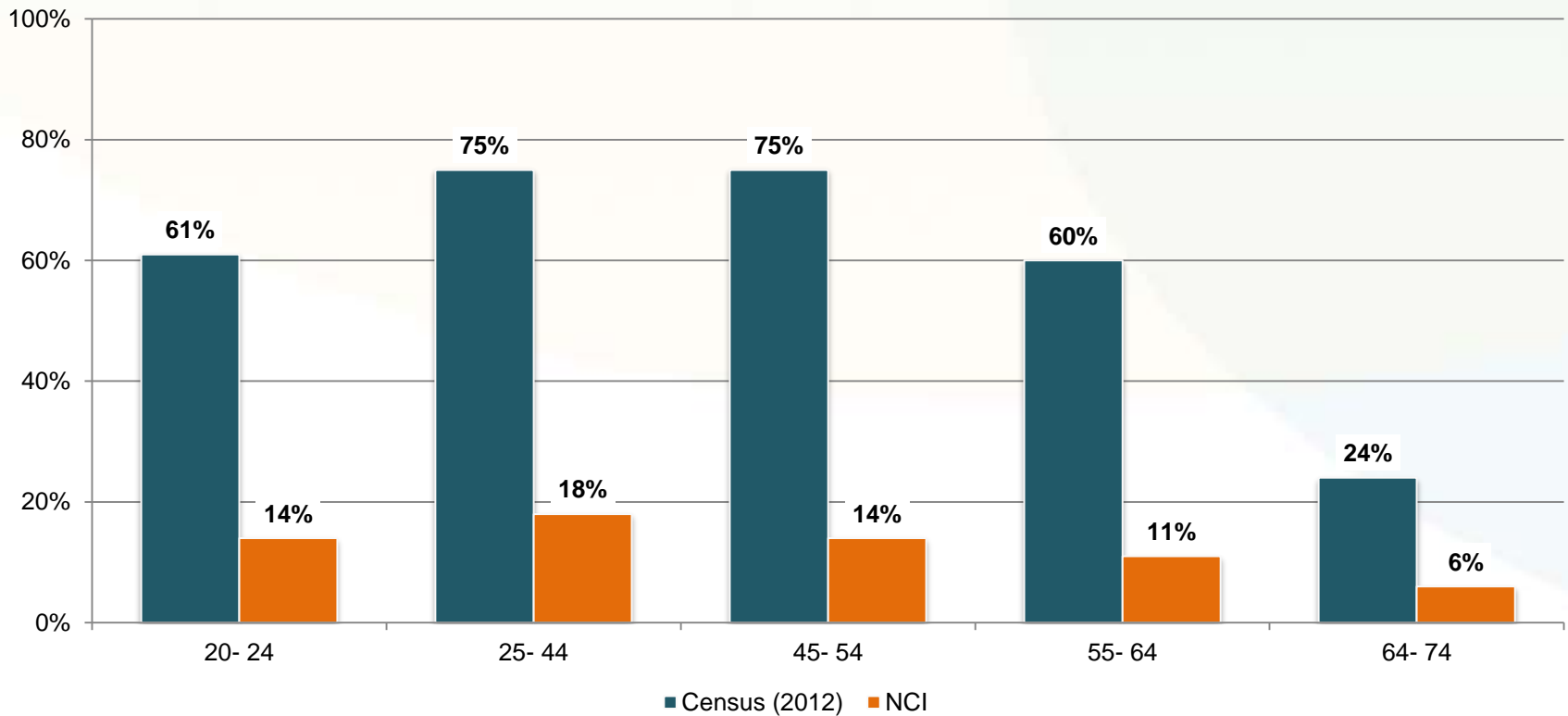


Source: <http://www.bls.gov/news.release/empsit.t01.htm>



Employment

Employment by age group



Census data:

http://factfinder2.census.gov/faces/tableservices/jsf/pages/productview.xhtml?pid=ACS_12_1YR_S2301&prodType=table



Loneliness

General Population*:

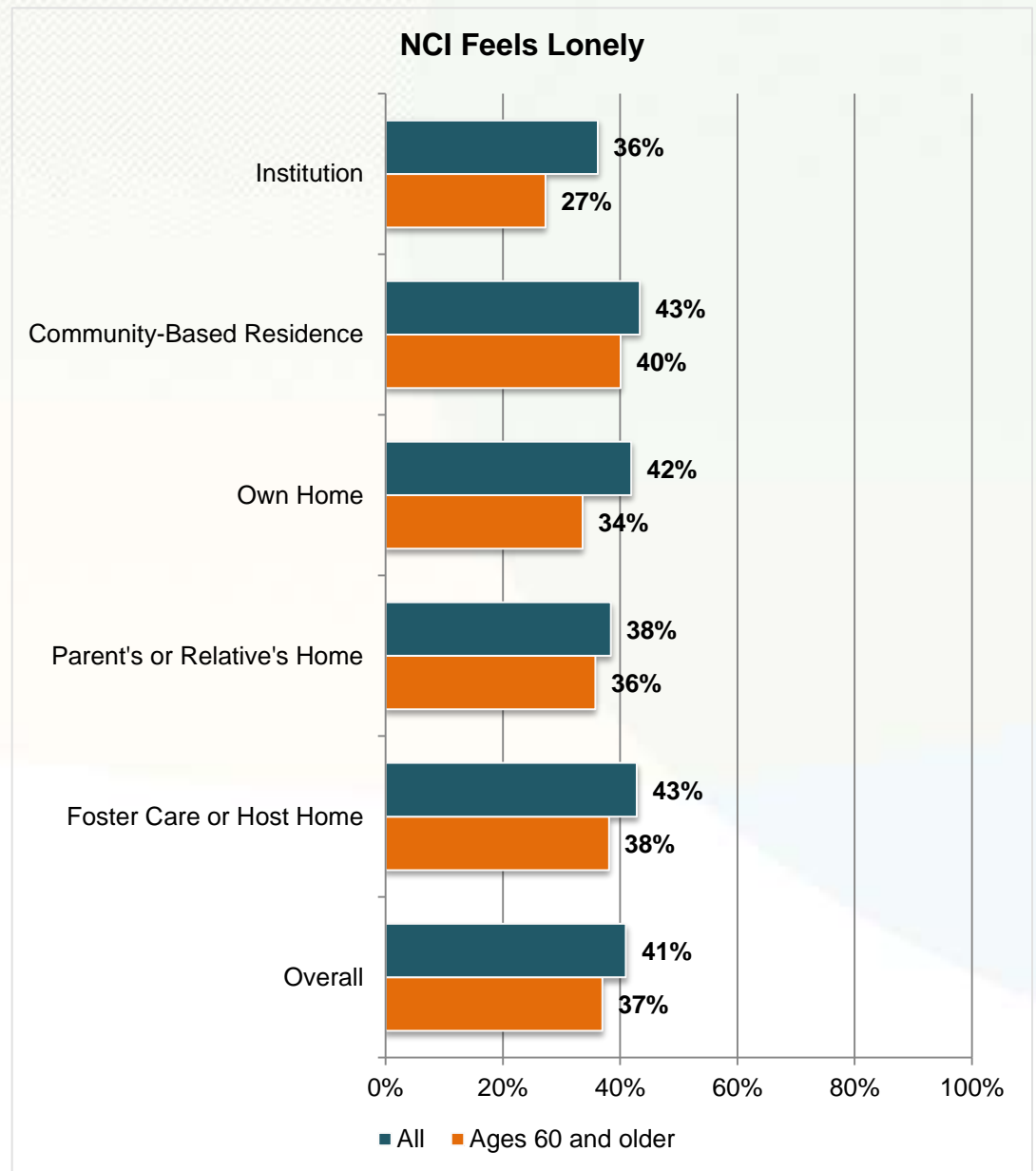
- 20% feel lonely

Older Adults (60+)**:

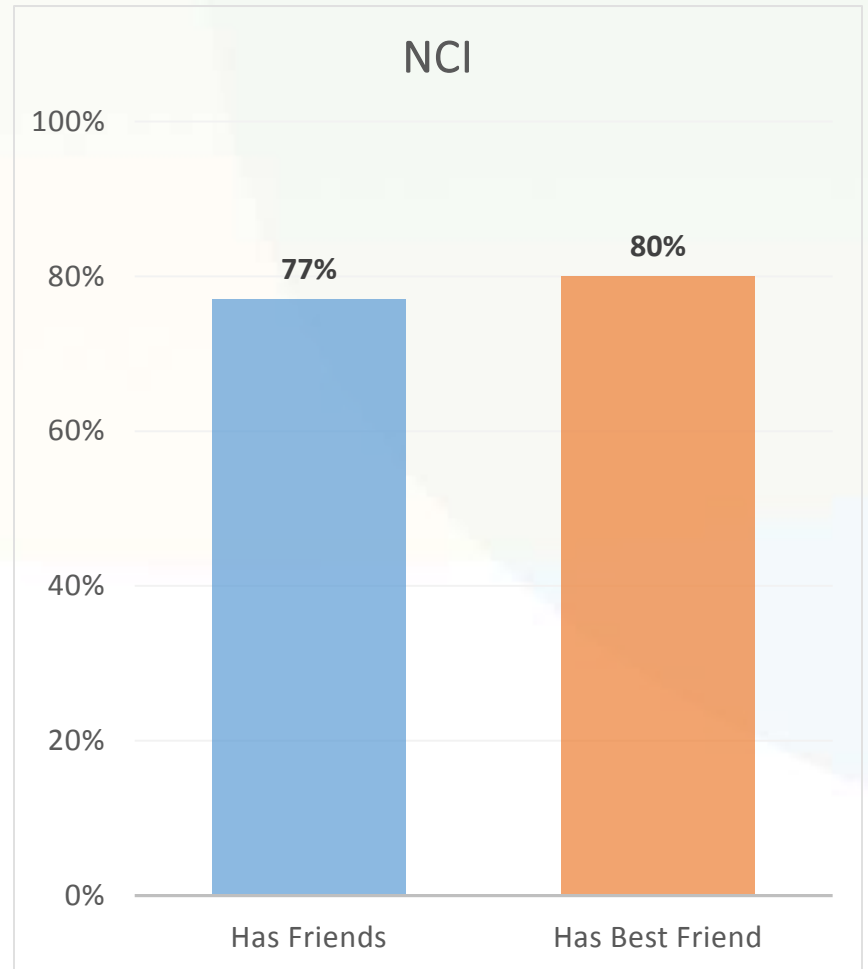
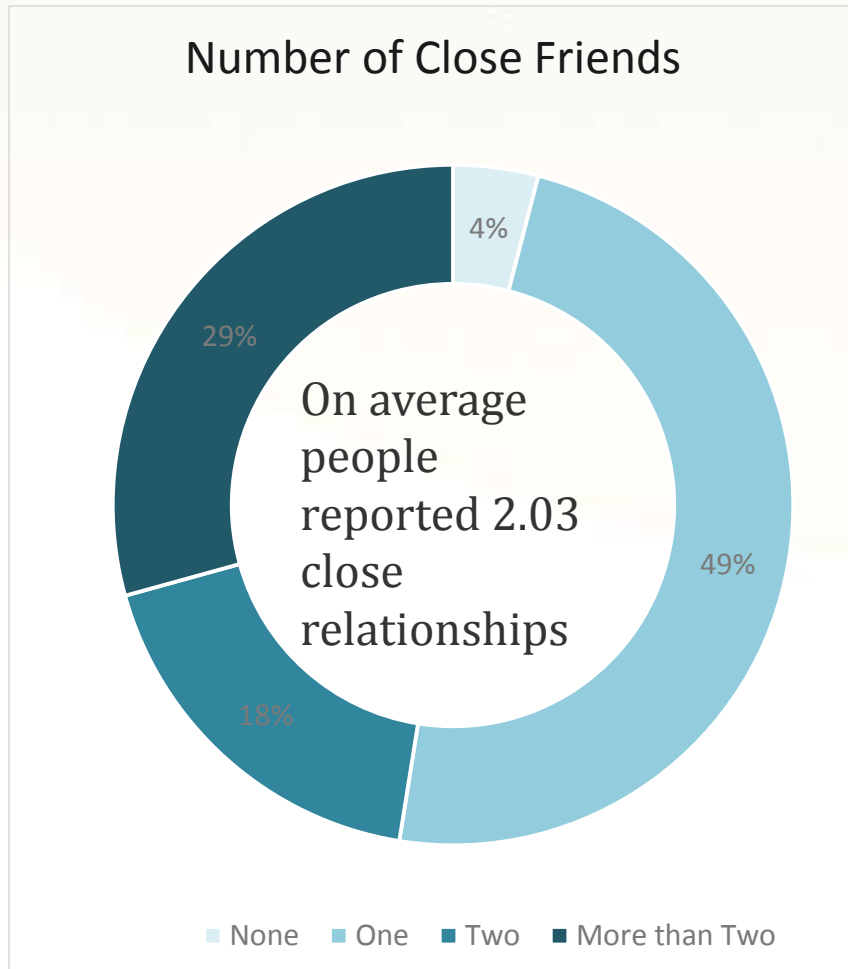
- 43% feel lonely
- 18% who feel lonely live alone

*Cacioppo, John; [Patrick, William](#), *Loneliness: Human Nature and the Need for Social Connection*, New York : W.W. Norton & Co., 2008

**Perissinotto CM, Stijacic Cenzer I, Covinsky KE. Loneliness in Older Persons: A Predictor of Functional Decline and Death. *Arch Intern Med.* 2012;172(14):1078-1084. doi:10.1001/archinternmed.2012.1993.



Friendship



Source: <http://www.nbcnews.com/health/health-news/you-gotta-have-friends-most-have-just-2-true-pals-f1C6436540>



How States Use NCI Data



Policy Planning

Service Development

Program Operation

Quality Management



NATIONAL CORE INDICATORS

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



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

- NCI Staff have prepared a publication, Practical Tools for States (Pell, 2014), to assist policy makers to monitor new CMS requirements including:
 - I. New HCBS Requirements and NCI Data**
 - II. New HCBS Requirements and NCI Data: Quick View Tables**
 - III. Revised HCBS Assurances and Sub-assurances and NCI Performance Indicators**



I. New HCBS Requirements and NCI Data

- New HCBS Setting Requirements (Residential and Day Services)
- New HCBS Setting Requirements for Provider Owned/Operated Residential Settings
- New HCBS Person-centered Service Plan Process Requirements
- New HCBS Person-centered Service Plan Documentation Requirements



Requirement: Provides opportunities to seek employment and work in competitive integrated settings, engage in community life, and control personal resources

NCI Data:

- If person has a job in community (ACS, [Employ/Day](#))
- If person does not have a job in the community, do they want one? (ACS, [Employ/Day](#))
- Of people employed, if they like their job and if they want a different job. (ACS, [Employ/Day](#))
- If person has integrated employment as a goal in their service plan. (ACS, [Background Info](#))



Requirement: Home is chosen by the individual from among residential and day options that include generic settings

*NCI data are useful for demonstrating **some** aspects of alignment with this requirement (e.g., NCI does not cover whether generic settings were offered)
NCI does collect data on residence type which includes generic settings such as family home, independent apartment*

NCI Data:

- Choice data are available by the type of home where the individual lives.
- If person chose their residence, work and/or day services (ACS, Choice)
- Did you/your family member choose the provider agencies who work with your family? (AFS & FGS, Choice & Control)
- Can you/your family member choose a different provider agency if s/he wants to? (AFS & FGS, Choice & Control)



Requirement: Privacy in their unit including entrances lockable by the individual (staff have keys as needed)

*NCI data are **useful in part** for demonstrating compliance. NCI does not cover lockable entrances or control of keys.*

NCI Data:

- If others announce themselves before entering home (ACS, Home)
- If others announce themselves before entering bedroom? (ACS, Home)
- If person has enough privacy (ACS, Home)



II. New HCBS Requirements and NCI Data: Quick View Tables

HCBS Setting Requirements	NCI - System Level Data
Is integrated in and supports access to the greater community	X
Provides opportunities to seek employment and work in competitive integrated settings, engage in community life, and control personal resources	X
Ensures the individual receives services in the community with the same degree of access as individuals not receiving Medicaid HCBS	--
Allows full access to the greater community	X
Is chosen by the individual from among residential and day options that include generic settings (Choice of provider in provider owned and operated settings guidance- CMS clarified that choice of provider is intrinsic to the setting.)	X (in part)



III. Revised HCBS Assurances and NCI Performance Indicators

Service Plan Sub-Assurances	NCI Performance Indicators
<p>i. Service plans address all members' assessed needs (including health and safety risk factors) and personal goals, either by the provision of waiver services or through other means.</p>	<p>NCI data sources contribute in part to meeting this sub-assurance. Sub-assurance has two components: 1) whether plans include an individual's personal goals and 2) if the individual's assessed needs are addressed in the plan.</p> <p>Adult Consumer Survey</p> <ul style="list-style-type: none">● Proportion of individuals who report that they do not get the services that they need● Proportion of people reporting that service coordinators ask them what they want.● Proportion of people reporting that service coordinators help them get what they need. <p>Family Surveys</p> <ul style="list-style-type: none">● Proportion of families who report their family member has a service plan that the family and/ or family member helped create, the plan meets the needs of the family/individual, and includes things that are important to the family.● Proportion of families who report that services/supports are available when needed and meet the family's needs, including in a crisis.

How Are States Using NCI Data in Policy Planning?

Strengthening Service Delivery and Quality System-Wide

- 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



QI Examples from Arizona



What AZ Does with Survey Data

- Charts data longitudinally from year to year to identify issues
- Presents survey findings to Statewide Management Team to identify areas of improvement
- Develops and implements district and/or statewide strategies for improvement (e.g., increasing provider rates to incentivize community and supported employment initiatives)
- Uses NCI data to evaluate progress with implemented strategies



What AZ Does with the Data

- Data from NCI surveys directly contributed to the creation and allocation of District Employment Specialist positions
- Survey results are posted to the Division's webpage
- Survey data are presented to the DES Director's Office, legislative staff, State Medicaid Agency, Division's Quality Management Committee, Governor's Council on Developmental Disabilities, Provider and Advocacy Agencies.
- Data shared with the Arizona Legislature and contributed to the creation of performance pay incentives for Department staff.



Other States Using NCI Data

- Alabama's Division of Developmental Disabilities
 - Uses the overall satisfaction number and employment numbers in their SMART Plan which is a budgeting and planning process through the Governor's office to gauge their success in meeting national benchmarks.
 - Currently conducting a pre/post survey analysis of people leaving Alabama's last developmental center
 - A Summary is forwarded to providers and they are encouraged to use findings to include in their own agency Quality Plans.



Planning for Employment in MD

MD ranks higher than average in individuals who would like a job in the community.

MD also ranks higher than average in individuals who have community employment as a goal in their service plan.

People would like a job in the community				
State	Overall In State	Community-Based	Individual Home	Parent's Home
MD	64%	68%	n/a	59%
NCI Average	49%	51%	45%	48%
People have community employment as a goal in their service plan.				
State	Overall In State	Community-Based	Individual Home	Parent's Home
MD	40%	25%	61%	52%
NCI Average	24%	21%	37%	23%



- Washington's Division of Developmental Disabilities
 - The Developmental Disabilities Council convened a review panel of self-advocates, family members, community providers and other professionals to review the results of the NCI survey data.
 - As a result of their work, the review panel make recommendations to the Division



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

Special Projects

NCI can be used beyond the sample size of 400 when...

- States want to track a particular population
- States want to compare systems within the state
- States want to ask additional questions

NCI Website

- **State Reports**
- **Annual Reports**
- **Data Briefs**
- **Articles**
- **National data**
- **Chart function**
- **Technical reports**



Core Indicators Drive Improvement

The **core indicators** are the foundation of the effort. The current set of performance indicators includes approximately 100 consumer, family, systemic, cost, and health and safety indicators.

Participating states pool their resources and knowledge to create performance monitoring systems, identify common performance indicators, work out cooperative data collection strategies, and **share results in order to understand the overall health of public developmental disabilities agencies.**



NCI Data Used by Self-Advocates and Families

by Josh Engler

HRI and NASCOOS staff were in the beautiful state of Washington last week to observe Lisa Weber and the rest of the WA NCI team in action. Part of the agenda included attending a CO Council focus group meeting. This meeting was made up of self-advocates, family members of children with developmental disabilities, and...

[READ MORE](#)

Featured Core Indicators

Understanding the overall health of public developmental disabilities agencies

Indicator Name or Description

Brief description of featured indicator that encapsulates the importance of the indicator.

[MORE](#)

Indicator Name or Description

Lorem ipsum dolor sit amet, consectetur adipiscing elit. Integer a scelerisque nisl in Massachusetts.

Suspendisse quis turpis dapibus. Praeent enim, semperque a fames a, phantasia non enim. Vivamus elit diam, pellentesque non lobortis ac, eleme ac enim. Etiam sagittis metus ac nulla sodales et sagittis magna euismod.

[Link One](#)

[Link Two](#)

Participating NCI States

Select a participating state to view its profile:



November 2010 Report Released: National Core Indicators (NCI) 2008-09 Annual Summary Report

HRI and NASCOOS are pleased to announce the release of the National Core Indicators 2008-09 Annual Summary Report. The Annual Summary Report highlights selected aggregate results from several of the NCI data sources...

[READ MORE](#)