# Quality of Life Data and Trends

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AAIDD Conference, Louisville, KY
June 2, 2015

*Sustaining Excellence—Making Progress*

# Provider Performance and Driver Outcomes

## Provider Systems That Predict Key Outcomes for Individuals

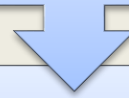## Delmarva Foundation

## Sue Kelly, Senior Scientist

Delmarva Foundation
Georgia Quality Management System

# Overview

**Quality Assurance/Improvement Programs in FL and GA**

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**Individuals with IDD receiving HCBS Waiver or State Funded Services**

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**Person Centered and Provider Reviews**

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**Conduct individual and staff interviews, observations, and record reviews**

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**Outcome Predictors:  Driver Outcomes and Provider Performance**

GQMS

## Person Centered Reviews (PCR)

- **Start with interviewing the person**
- **Determine quality of supports & services, and**
- **How well person is supported to meet goals**

## Provider Reviews (PDR, QEPR)

- **Multi faceted approach**
- **Assess compliance with standards**
- **Evaluate person centered practices for individuals served**
- **Evaluate overall service delivery systems**

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# Results from Florida Study

Analysis in 2006 indicated several provider performance areas that best predict the percent of Personal Outcome Measures (POM) present:

- **Communication**
  - Importance of interaction among providers
  - Create an environment of cohesive action
  - Outcomes are everyone's responsibility
- **Ensuring individuals are developing desired social roles**
- **Ensuring individuals have privacy**

# Results from Georgia Study

**2012 analysis showed significantly more outcomes when provider documentation showed:**

- **How person is given choice of services and supports**
- **Efforts to support person to develop social roles**
- **Person's progress in achieving desired goals**
- **Person centered focus**
- **A clear description of services and supports provided**
- **How supports/services change as needed**

Provider Systems and Driver Outcomes
Georgia Quality Management System
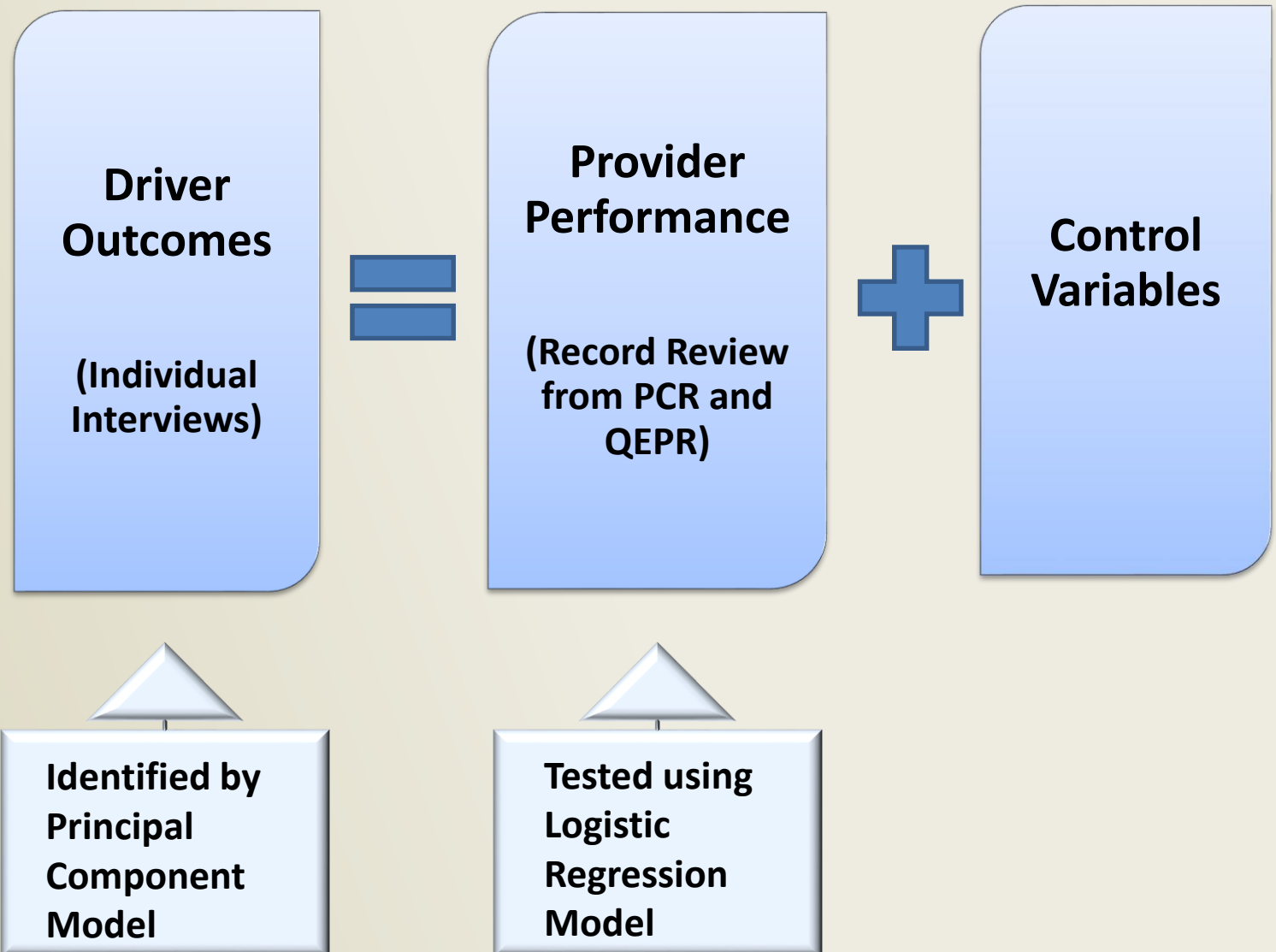
# Individual Interview Outcomes
## 6 Focused Outcome Areas (15 indicators)
## Develop Driver Outcomes

# Strongest Driver Outcome
## Person Centered Planning

✓ **The person is afforded choice of services and supports.**

✓ **The person is involved in the design of the service plan.**

✓ **The person's goals and dreams are reflected in supports and services.**

✓ **The person is achieving desired outcomes and goals.**

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# Second Driver Outcome
## Community Integration and Rights

- ✓ **The person actively participates in decisions concerning his or her life.**

- ✓ **The person is educated and assisted to learn about and exercise rights.**

- ✓ **The person has opportunities to access and participate in community activities.**

- ✓ **The person is developing desired social roles.**

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# Provider Record Reviews
# To Identify Predictors

- **15 indicators represent each Focused Outcome Area**

- **Assess the quality of provider documentation**

- **Review records for all services the individual receives**

- **Documentation shows  how well providers implement policies and support individuals served**

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# Logistic Regression Model

Dependent

Person Centered Planning

Community /Rights
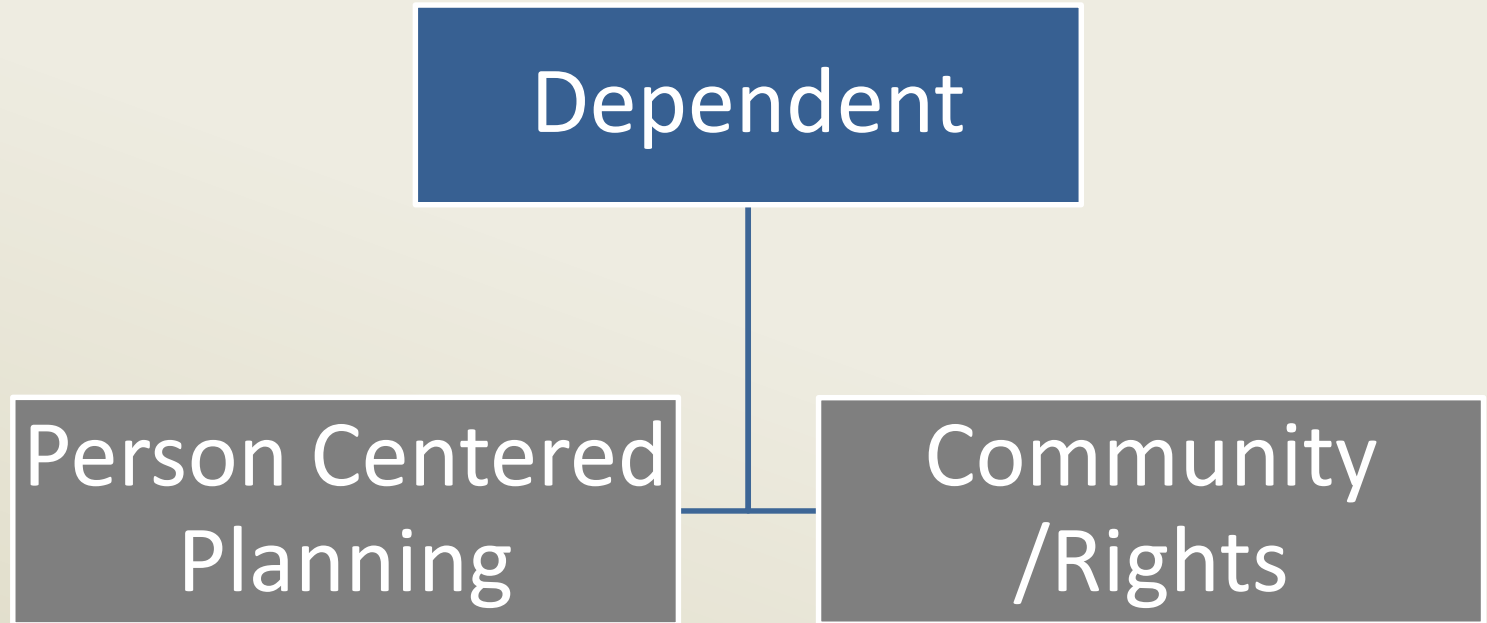
# Logistic Regression Model

- **Explanatory/Independent Variables**
  - **Residence**
  - **Age**
  - **Disability**
  - **Region**
  - **Service**

  **Control Variables**

  - **PPR Indicators of provider performance**

# Strongest PRR Predictors
## (OR = PCP and C/R Odds Ratio)

Strongest predictor of both driver outcomes is if the person is provided a choice of community services and supports (OR 2.52, 3.54)

If provider ensures a choice of services and supports, person is much more likely to have both driver outcomes (OR 2.20, 2.23)

If documentation shows providers assist person to direct supports and services, both driver outcomes are more likely to be present (OR 1.91. 1.86)

# Strongest PRR Predictors
## (OR = PCP and C/R Odds Ratio)

Providers who use a person centered focus in their documentation positively impact driver outcomes (OR 1.70, 1.68)

Documenting how the person is progressing toward and achieving desired goals positively impacts driver outcomes (OR 1.57, 1.56)

Having the means to identify health status and safety needs increases the persons community integration (OR 1.77)

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# Other Findings

**Receiving Supported Employment is more beneficial than any other service in supporting Community/ Rights driver outcomes**

**People living in group homes were less likely to have elements of both driver outcomes present**

**People with Mild/Moderate ID were about 40% more likely to have Community Integration/Rights driver outcomes present than individuals with Profound ID**

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# Key Findings

- **Elements of Person Centered Planning are the most important driver outcome—impact presence of other outcomes**

- **Findings show importance of having the person involved in planning and choosing services that reflect desired goals.**

# Key Findings

- **Providers who offer choice of services and supports, choice of community supports, and ensure the person directs services are 2 to 2.5 times more likely to impact Person Centered Planning outcomes, and thus the overall quality of life for the person**

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# Contacts

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## About CQL | The Council on Quality and Leadership

- What does the data tell us:
  - 20 years of Personal Outcome Measures® Data
  - Looking at predictor outcomes
  - Measuring Social Capital with POM

- How is the information being used

## ABOUT CQL

# CQL's work centers around 3 tools:

## Personal Outcome Measures®

- Developed in 1997
- Values-based, individualized quality of life measurement tool
- Valid and reliable assessment
- 21 factors measuring outcomes and presence of supports
- Used in accreditation, person-centered planning, ISPs, organizational learning, state reporting

## Basic Assurances®

- Provider level regulatory review
- Person-centered approaches intertwined with regulation
- 10 Factors and 46 sub-factors
- Indicators evaluated using two measures: System in Place and System in Practice
- Used in accreditation and state reporting
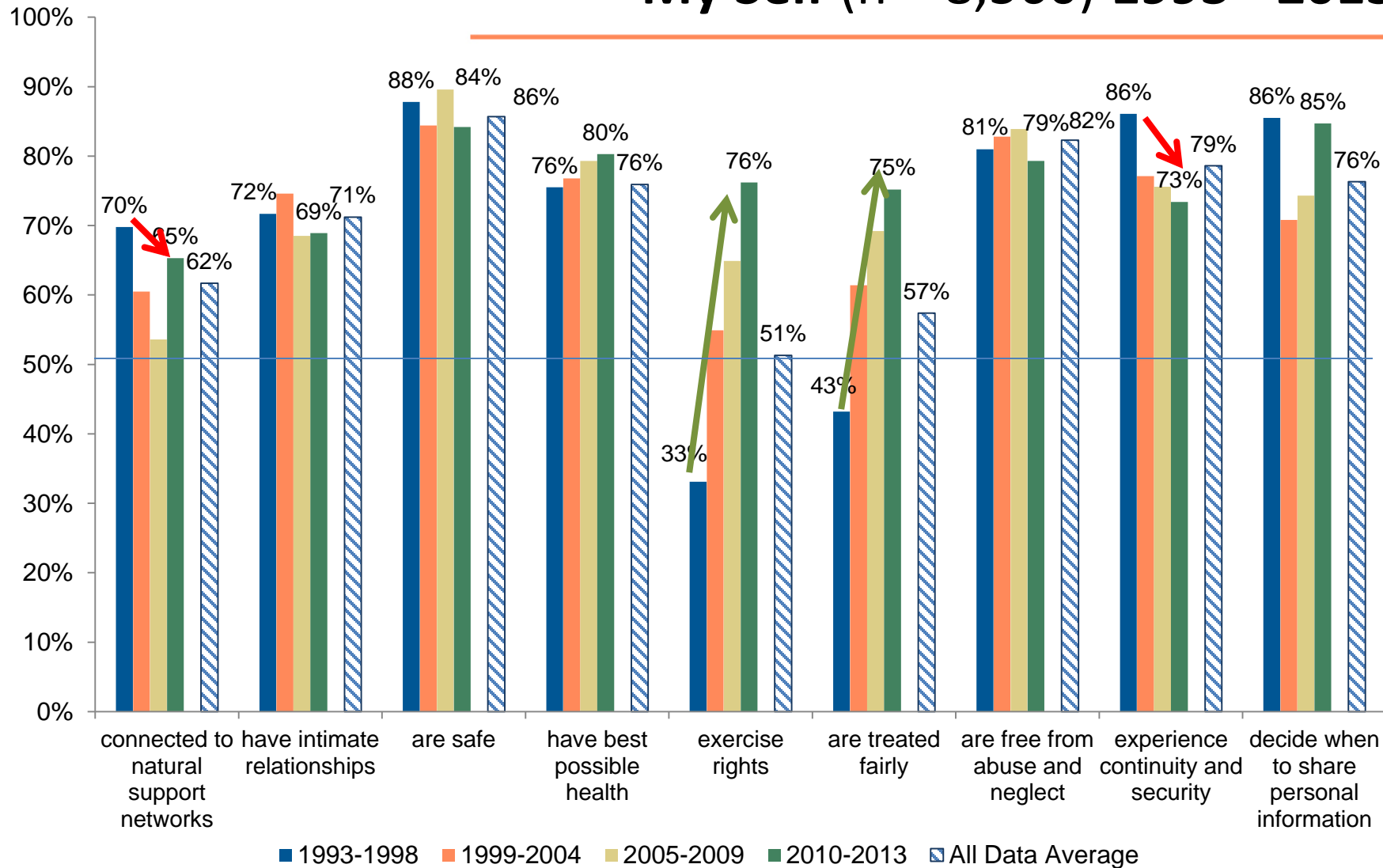
## Person-Centered Excellence

- Multi-stakeholder assessment of provider level performance
- Used in provider level strategic planning
- 8 key factors and 34 success indicators focused on Person-Centered Excellence
- All indicators meant to drive better accountability in services, greater choice and community inclusion

## LOOKING AT THE POM DATA

## Overview of CQL Data Collection

- All POM data presented comes from:
    - CQL Certified Interviewers
    - CQL Staff

- Records are not necessarily the same people from year-to-year

- Data used to show trends in services

- More finite research can be conducted at the individual, provider and/or state by state level
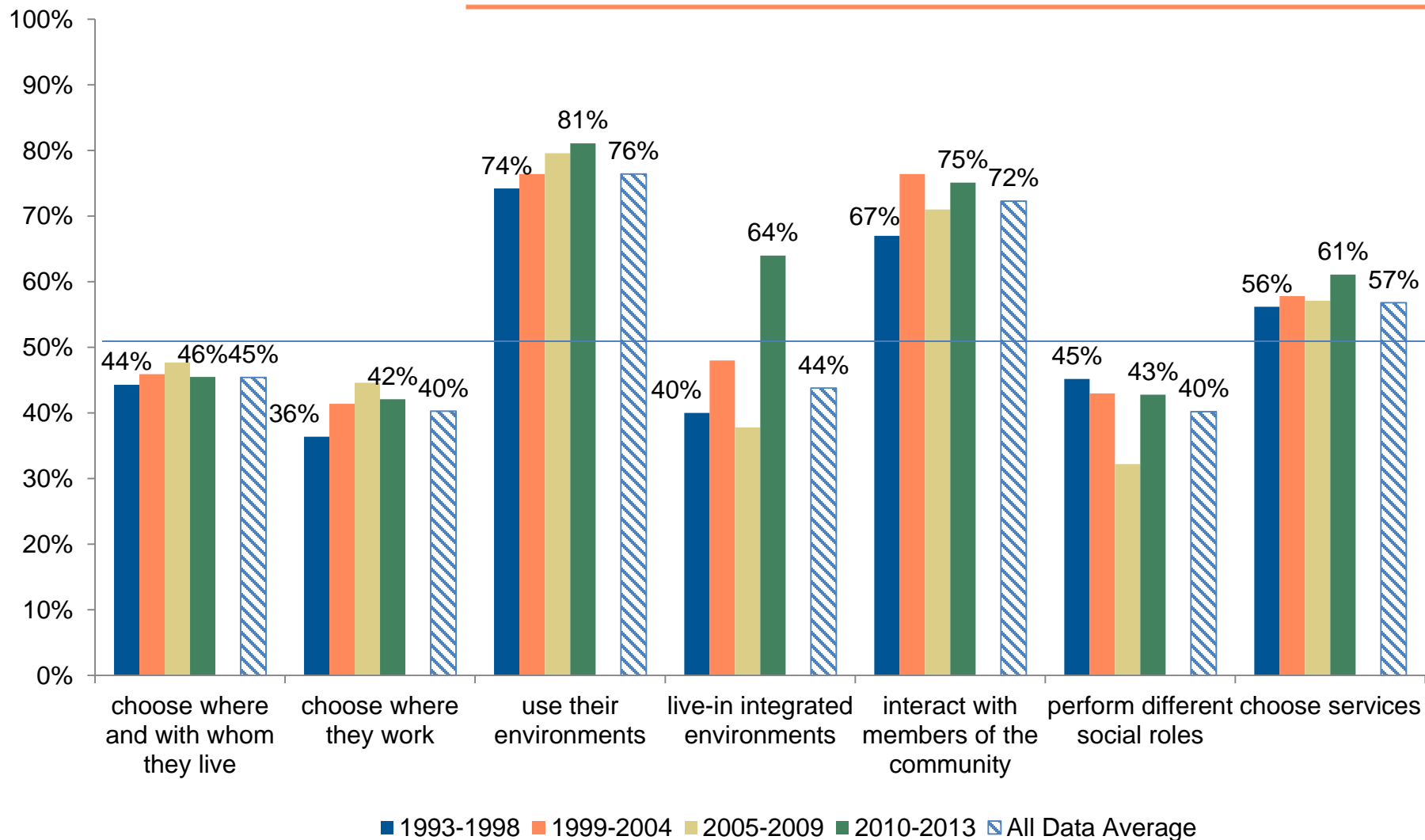
## My Self (n = 8,560) 1993 - 2013



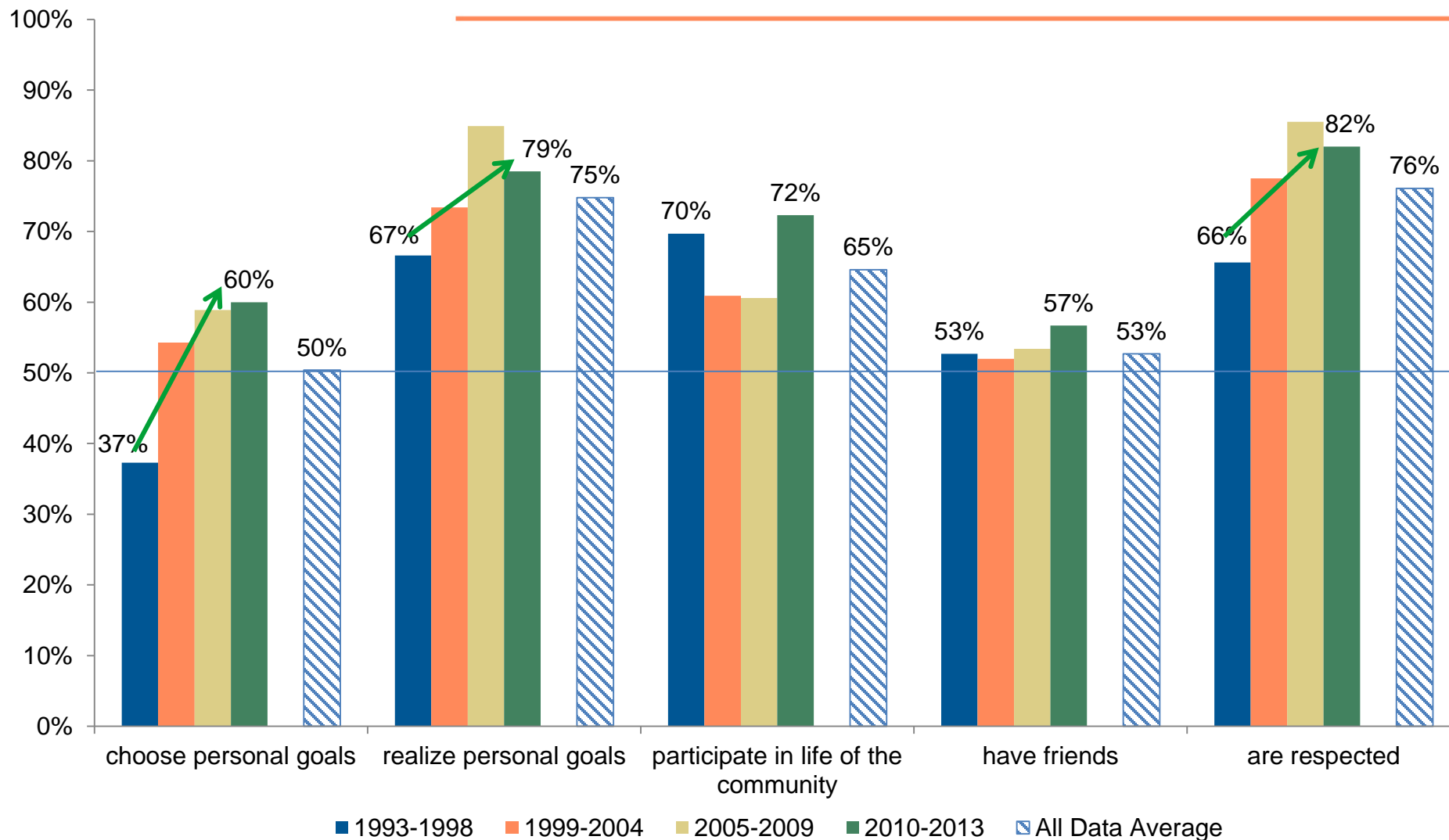Chart legend: 1993-1998, 1999-2004, 2005-2009, 2010-2013, All Data Average

| Category | Values |
|---|---|
| connected to natural support networks | 70%, 65%, 62% |
| have intimate relationships | 72%, 69%, 71% |
| are safe | 88%, 84%, 86% |
| have best possible health | 76%, 80%, 76% |
| exercise rights | 33%, 76%, 51% |
| are treated fairly | 43%, 75%, 57% |
| are free from abuse and neglect | 81%, 79%, 82% |
| experience continuity and security | 86%, 73%, 79% |
| decide when to share personal information | 86%, 85%, 76% |

## My World (n = 8,560) 1993 - 2013



Legend: ■ 1993-1998  ■ 1999-2004  ■ 2005-2009  ■ 2010-2013  ▨ All Data Average

## My Dreams (n = 8,560) **1993 - 2013**



Legend: ■ 1993-1998  ■ 1999-2004  ■ 2005-2009  ■ 2010-2013  ▨ All Data Average

Categories and values:
- choose personal goals: 37%, 60%, All Data Average 50%
- realize personal goals: 67%, 79%, All Data Average 75%
- participate in life of the community: 70%, 72%, All Data Average 65%
- have friends: 53%, 57%, All Data Average 53%
- are respected: 66%, 82%, All Data Average 76%

## PREDICTORS

# Specific Outcomes Correlated With Total Outcomes

| HIGHEST | |
|---|---|
| Exercise Rights | .537 |
| Are Treated Fairly | .523 |
| Choose where and with whom they live | .517 |
| Interact with members of the community | .501 |
| Choose where they work | .499 |
| **LOWEST** | |
| Decide when to share information | .337 |
| Have the best possible health | .310 |
| Free from abuse and neglect | .284 |
| Experience continuity and security | .276 |
| Are safe | .192 |

n = 7,806
* All correlations are significant at the 0.05 level (2-tailed)

## SOCIAL CAPITAL AND POMS

### Bonding Social Capital

Five personal outcomes make up the Bonding factor. These outcomes are entry points for developing social capital. They are related to our current world and the people and places we already know. They represent the initiation of bonds that make social capital more likely. They are the glue that holds us together.

### Bridging Social Capital

Three personal outcomes make up the bridging factor. They represent the connections we have to the world around us beyond the confines of who we already know, where we already go and what we already do. They represent potential for increased social ties and connections. They are the WD-40 of social interactions.

### Social Capital Index

Measuring their collective value enables us to make inferences about the level of social capital for organizations, people and communities. These inferences from the social capital index can facilitate change at the organizational and community level.

### BONDING

**People have intimate relationships**

**People participate in life of the community**

**People have friends**

**People are respected**

**People are connected to natural supports**
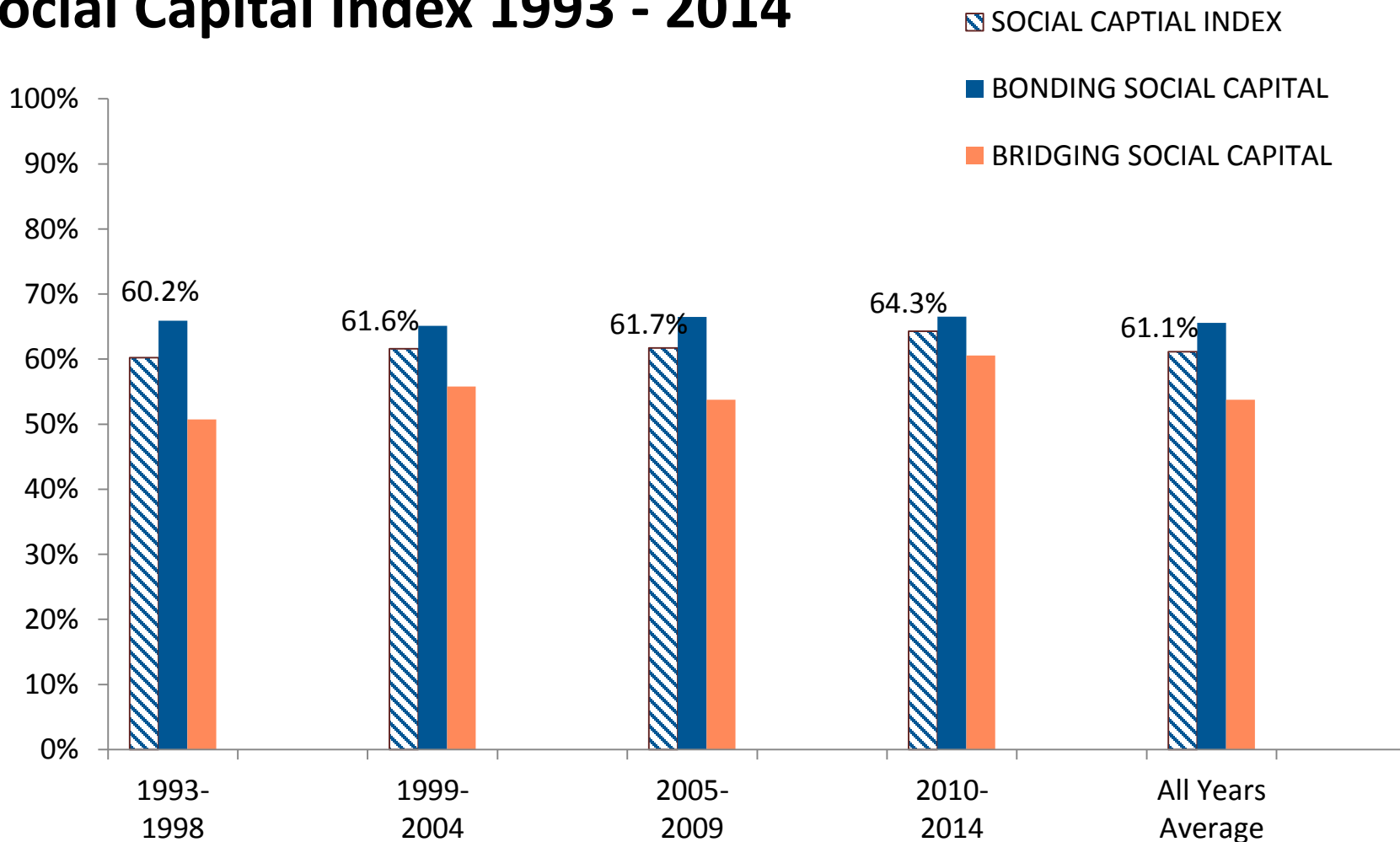
### BRIDGING

**People live-in integrated environments**

**People interact with members of the community**

**People perform different social roles**

## SOCIAL CAPITAL OVER THE YEARS

### Social Capital Index 1993 - 2014



Legend:
- SOCIAL CAPTIAL INDEX
- BONDING SOCIAL CAPITAL
- BRIDGING SOCIAL CAPITAL

Data labels (SOCIAL CAPITAL INDEX):
- 1993-1998: 60.2%
- 1999-2004: 61.6%
- 2005-2009: 61.7%
- 2010-2014: 64.3%
- All Years Average: 61.1%

## USING POMS

### Individual Level

- Information for the ISP
- Advocacy

### Provider Level

- Local Quality Monitoring (w/BA)
- Trend Analysis
- Accreditation

### State Level

- Aggregated Data for QA/QM
- Systems Learning and Monitoring
- CMS Reporting

**All users will have enhanced data and information due to the new extended online data system**

## NEW ONLINE POM DATA SYSTEM

- Extended demographics section
  - Aligning with other national data efforts
- Increased data points to identify what – if anything – is causing outcomes and/or supports to be present or not
  - Moved from 42 variables to 250+ variables
- No changes to the existing structure of the POM interview
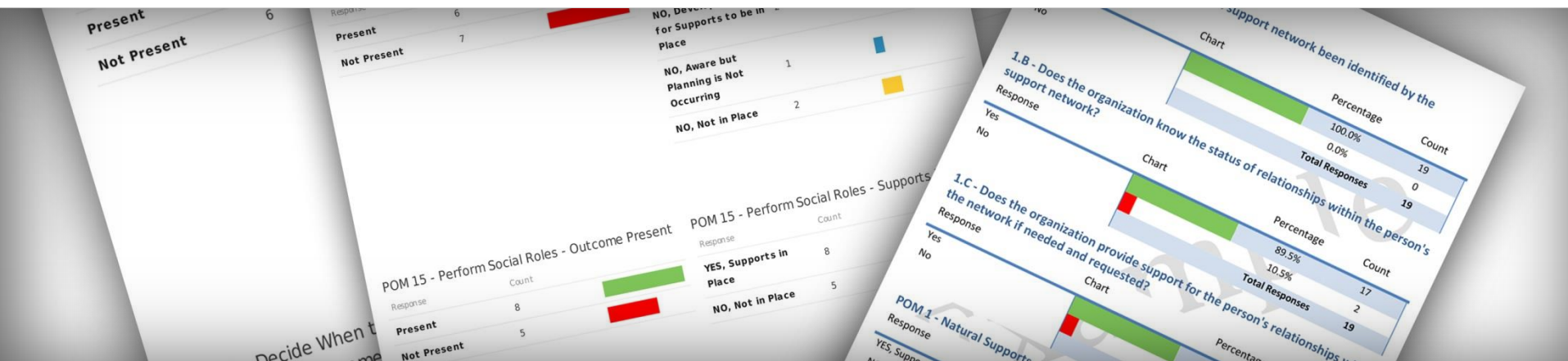
## NEW ONLINE POM DATA SYSTEM



POM 1 - Natural Supports - Outcome Present by Hours of Support (n= 72)

## NEW ONLINE POM DATA SYSTEM

**POM 5 - Exercise Rights- Outcome Present by Hours of Support (n = 68)**



■ Present
■ Not Present

## IN-DEPTH OUTCOME REVIEW
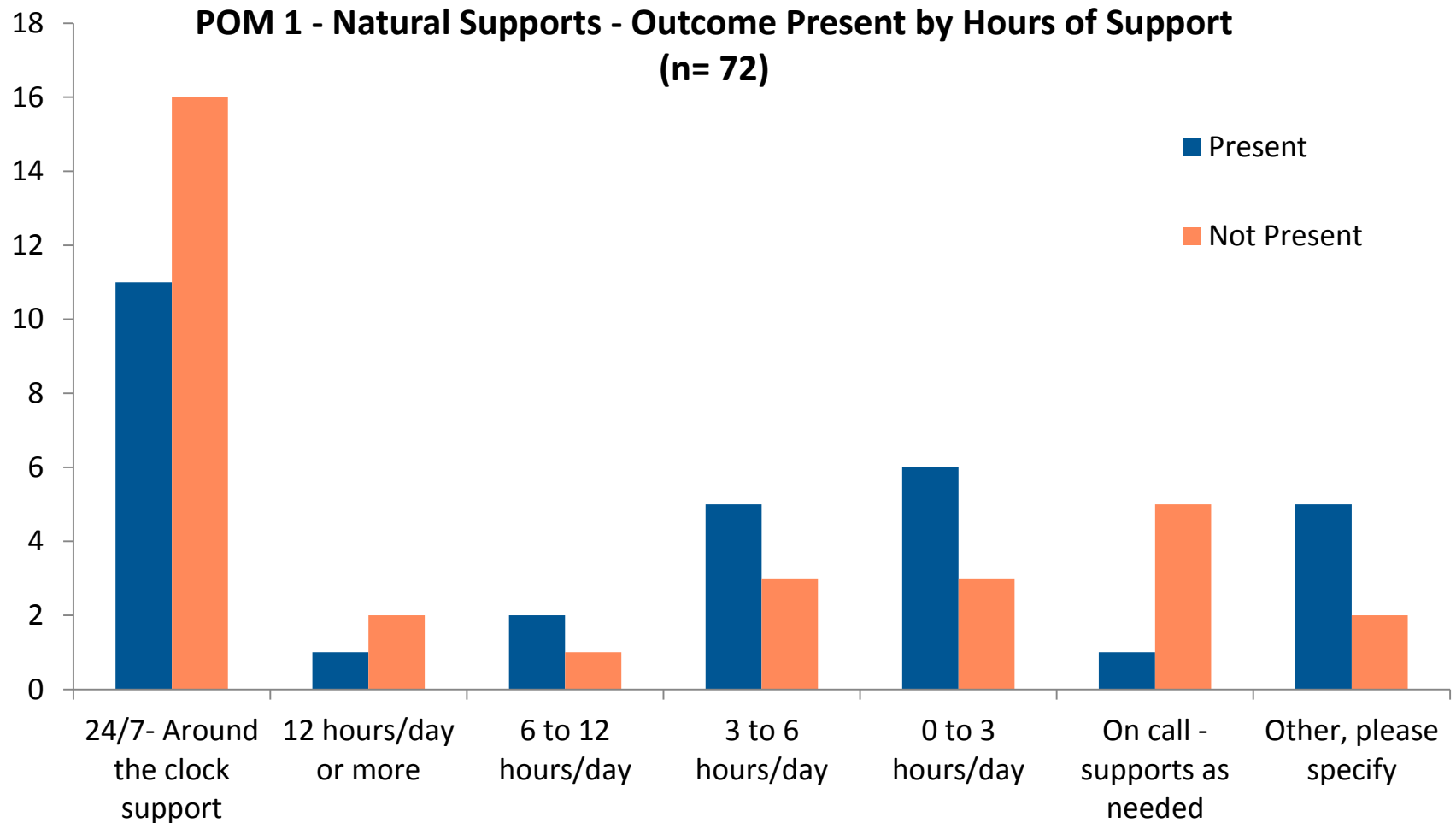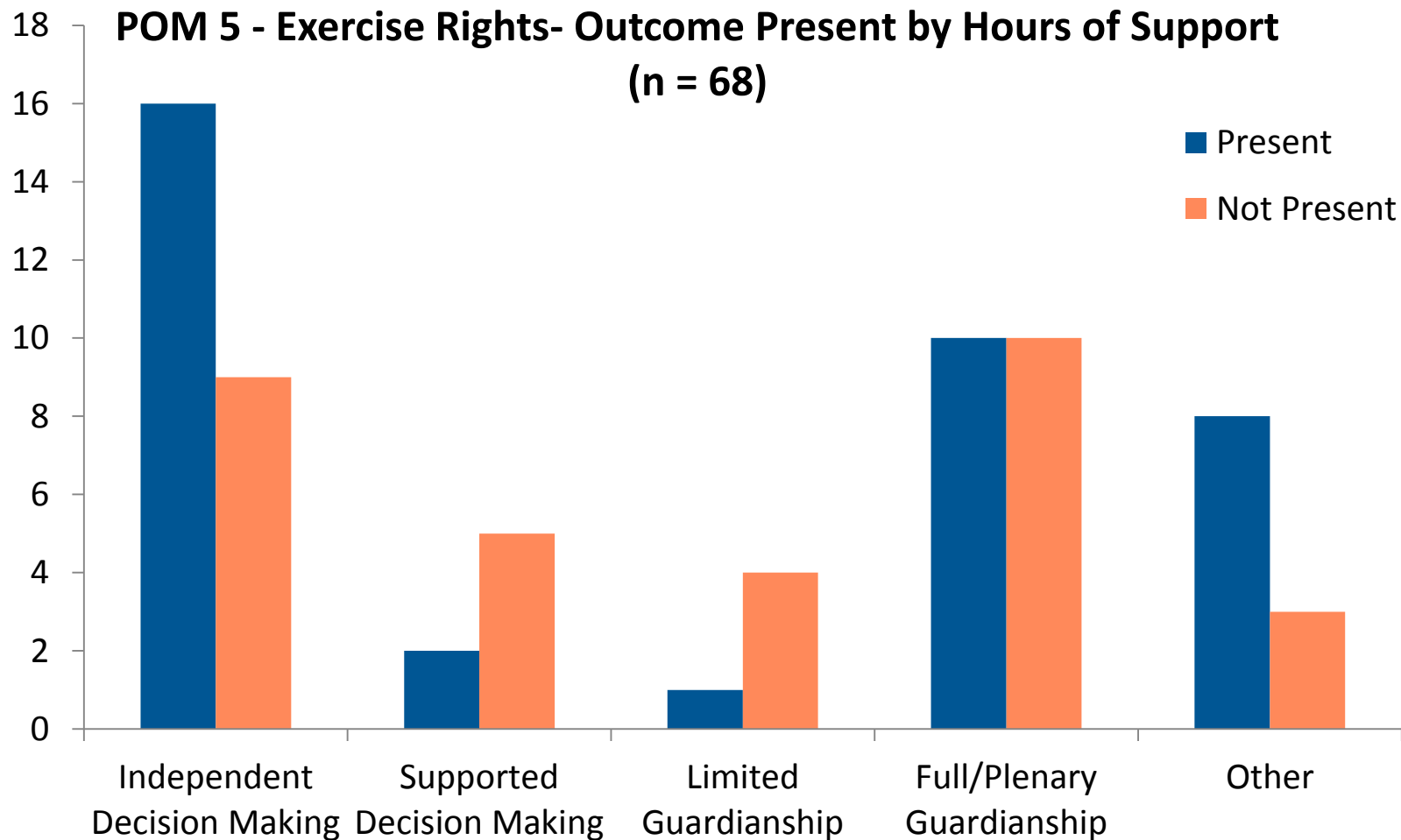
# People Exercise Rights

5.1 - Indicate whether the person exercises this right as a citizen?

| | Yes | No | Total Responses |
|---|---|---|---|
| Right to voice their opinion | 58 (80.6%) | 14 (19.4%) | 72 |
| Right to vote | 42 (61.8%) | 26 (38.2%) | 68 |
| Right to move about the community | 54 (78.3%) | 15 (21.7%) | 69 |
| Right to associate with others | 57 (81.4%) | 13 (18.6%) | 70 |
| Right to practice their religion | 53 (77.9%) | 15 (22.1%) | 68 |
| Right to privacy | 50 (73.5%) | 18 (26.5%) | 68 |
| Right to access their possessions | 58 (81.7%) | 13 (18.3%) | 71 |
| Right to access food/refrigerator | 45 (65.2%) | 24 (34.8%) | 69 |
| Right to have visitors at any time | 53 (75.7%) | 17 (24.3%) | 70 |
| Right to access their money | 46 (65.7%) | 24 (34.3%) | 70 |
| Right for personal decision-making | 48 (68.6%) | 22 (31.4%) | 70 |
| Right to fair wages | 35 (58.3%) | 25 (41.7%) | 60 |
| Right to non-discrimination at work | 45 (78.9%) | 12 (21.1%) | 57 |

5.1 – Who, if anyone, most limits the person's ability to exercise this right?

| | Guardian | Family | Provider org./support staff | Employer/co-worker | Other | Total Responses |
|---|---|---|---|---|---|---|
| Right to voice their opinion | 3 (14.3%) | 2 (9.5%) | 2 (9.5%) | 6 (28.6%) | 8 (38.1%) | 21 |
| Right to vote | 6 (19.4%) | 4 (12.9%) | 8 (25.8%) | 3 (9.7%) | 10 (32.3%) | 31 |
| Right to move about the community | 2 (7.1%) | 5 (17.9%) | 14 (50.0%) | 2 (7.1%) | 5 (17.9%) | 28 |
| Right to associate with others | 5 (23.8%) | 5 (23.8%) | 7 (33.3%) | 2 (9.5%) | 2 (9.5%) | 21 |
| Right to practice their religion | 4 (23.5%) | 5 (29.4%) | 3 (17.6%) | 2 (11.8%) | 3 (17.6%) | 17 |
| Right to privacy | 10 (40.0%) | 4 (16.0%) | 9 (36.0%) | 1 (4.0%) | 1 (4.0%) | 25 |
| Right to access their possessions | 9 (39.1%) | 7 (30.4%) | 6 (26.1%) | 0 (0.0%) | 1 (4.3%) | 23 |
| Right to access food/refrigerator | 9 (33.3%) | 3 (11.1%) | 10 (37.0%) | 2 (7.4%) | 3 (11.1%) | 27 |
| Right to have visitors at any time | 5 (25.0%) | 3 (15.0%) | 4 (20.0%) | 2 (10.0%) | 6 (30.0%) | 20 |
| Right to access their money | 3 (10.3%) | 3 (10.3%) | 11 (37.9%) | 2 (6.9%) | 10 (34.5%) | 29 |
| Right for personal decision-making | 11 (39.3%) | 6 (21.4%) | 4 (14.3%) | 2 (7.1%) | 5 (17.9%) | 28 |
| Right to fair wages | 11 (39.3%) | 2 (7.1%) | 10 (35.7%) | 2 (7.1%) | 3 (10.7%) | 28 |
| Right to non-discrimination at work | 2 (11.8%) | 2 (11.8%) | 3 (17.6%) | 3 (17.6%) | 7 (41.2%) | 17 |

## IN-DEPTH OUTCOME REVIEW
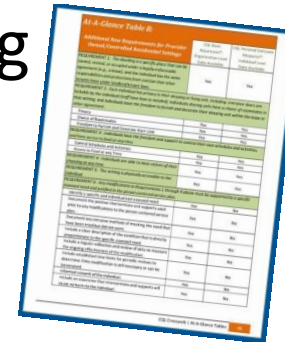
## People Experience Continuity & Security

| Response | Chart | Percentage | Count |
|---|---|---|---|
| Present | | 54.1% | 40 |
| Not Present | | 45.9% | 34 |
| | | **Total Responses** | **74** |

## ADDITIONAL RESOURCES

CQL Toolkit for States – CMS Reporting

**www.c-q-l.org/cmstoolkit**

20 Years of Personal Outcome Measures®

**www.c-q-l.org/resource-library/publications**

New Online POM Data System

**www.c-q-l.org/data**

CQL is dedicated to the definition, measurement and improvement of personal quality of life for people receiving human services and supports.

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# Agenda

- National Core Indicators
- NCI Outcomes Measurement: Relationship of Level of ID to Outcomes
  - How do outcomes differ for individuals with different levels of ID?
- Which indicators remain correlated through all levels of ID?
- Why is this important?
- Questions?

# What are the National Core Indicators?

# NATIONAL CORE INDICATORS (NCI)?

- NASDDDS – HSRI Collaboration
  - Multi-state collaboration of state DD agencies
  - Launched in 1997 in 6 participating states with a 15 state steering-committee – now in 42 states (including DC) and 22 sub-state areas
- Goal: Measure performance of public systems for people with intellectual and developmental disabilities
  - Help state DD systems assess performance by benchmarking, comparing to other states
- Assesses performance in several areas, including:
  - employment, community inclusion, choice, rights, and health and safety
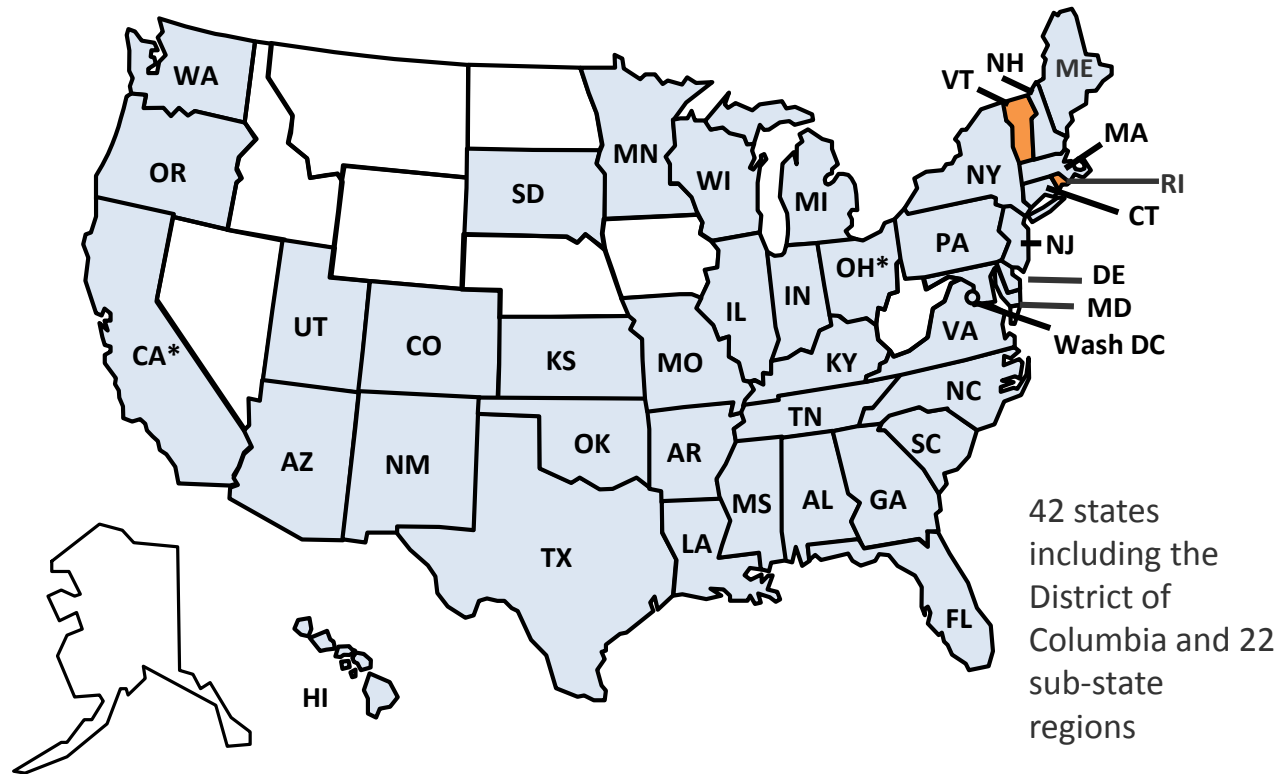- Now expanded to elderly and people with disabilities through the NCI-AD

# NCI is a Person-Centered Tool that Provides Information on:

- 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 State Participation 2014-15



42 states including the District of Columbia and 22 sub-state regions

■ State contract awarded in 2014-15 through AIDD funding

CA*- Includes 21 Regional Centers
OH*- Also includes the Mid-East Ohio Regional Council

# How Does NCI Collect Data?

- Adult Consumer Survey
  - ✓ In-person conversation with a sample of adults receiving services to gather information about their experiences
  - ✓ Keyed to important person-centered outcomes that measure system-level indicators related to: employment, choice, relationships, case management, inclusion, health, etc.
- Adult Family, Child Family, and Family/Guardian Surveys Mail surveys – separate sample from Adult Consumer Survey
- Other NCI state level data: Staff Stability

# NCI Outcomes Measurement: Relationship of Level of ID to Outcomes

# What are Outcomes and Indicators?

- Outcomes:
  - The changes for individuals or populations during or after participation in programs.
    - In the NCI context, outcomes include: choice, relationships, case management, inclusion, rights and respect, safety, etc.

- Indicators:
  - Ways to measure outcomes. Provides evidence that certain results have/have not been achieved.
    - For instance, the proportion of people who chose where they live; the proportion of people who can go on a date

# NCI Outcomes Are Influenced by Level of Disability

- Past analyses have shown that the variable that measures level of ID is significantly related to outcomes

- "[If this person is diagnosed with an ID], what level of ID?
  - __ 1 Mild ID
  - __ 2 Moderate ID
  - __ 3 Severe ID
  - __ 4 Profound ID
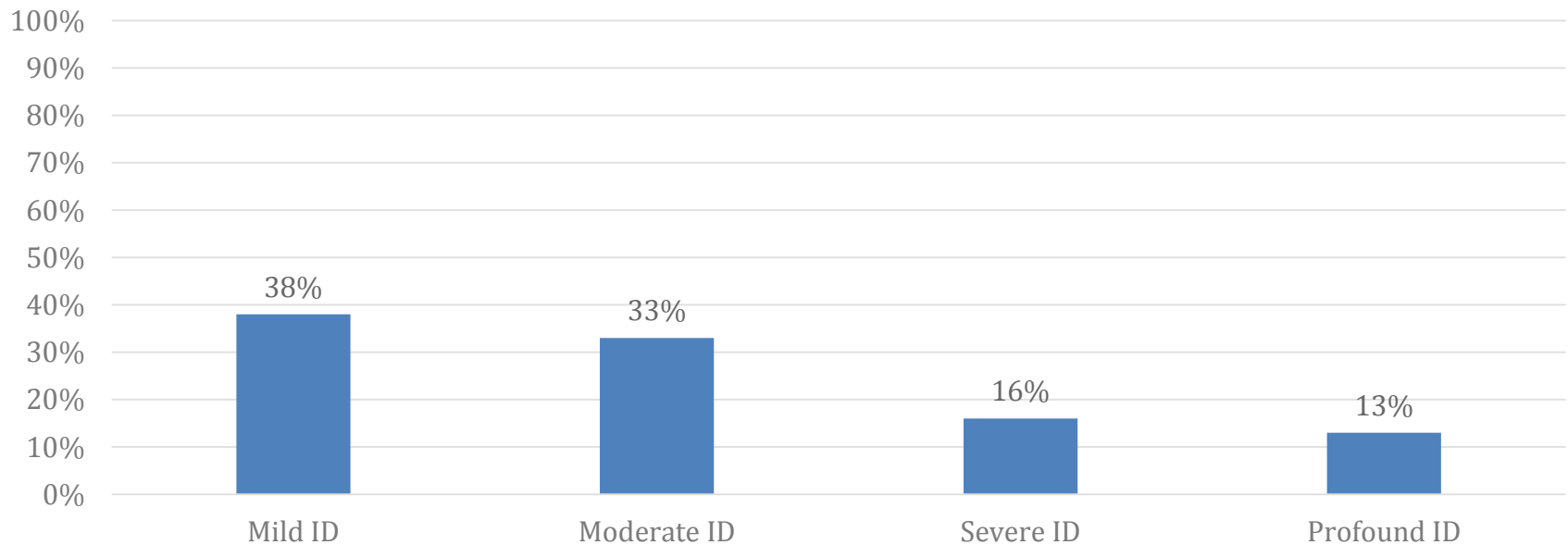  - __ *5 Unspecified level of ID*
  - __ *6 ID level unknown*"

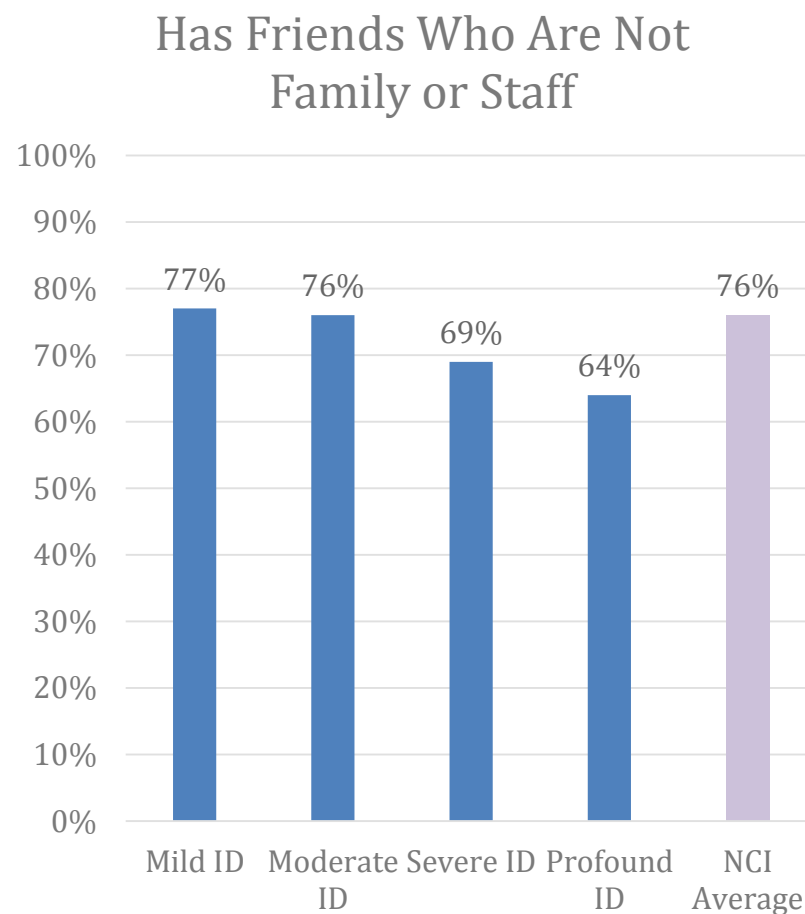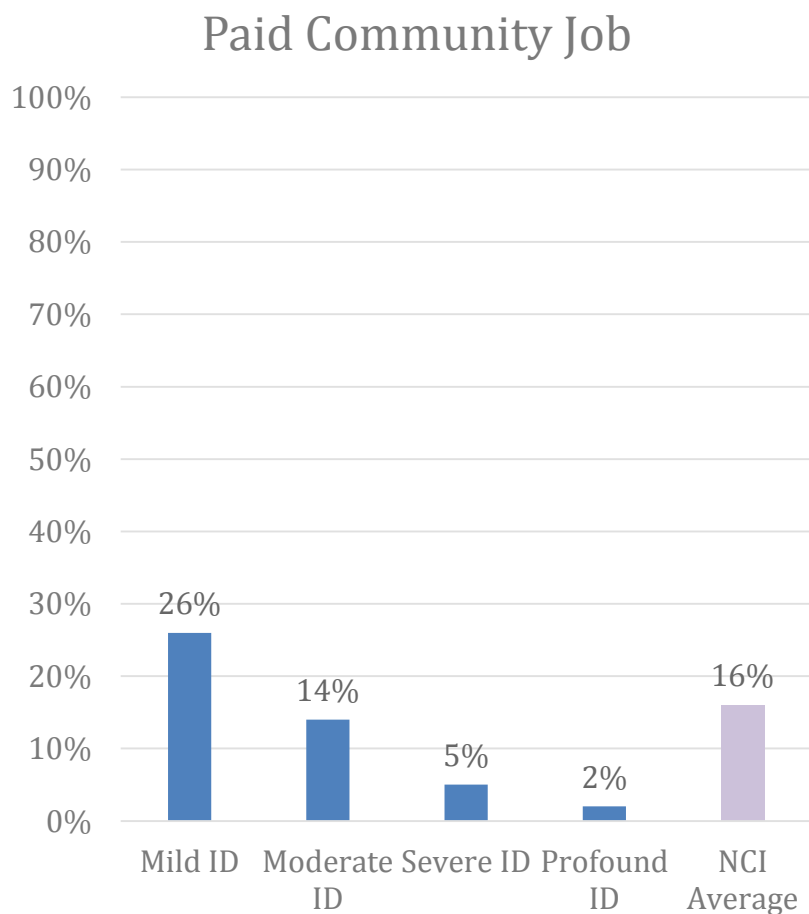# Residence, shown differently



Breakdown of Level of ID Within Each Residence Type

# Examples: Outcomes Vary by Level of ID



Paid Community Job

- Mild ID: 26%
- Moderate ID: 14%
- Severe ID: 5%
- Profound ID: 2%
- NCI Average: 16%

Has Friends Who Are Not Family or Staff

- Mild ID: 77%
- Moderate ID: 76%
- Severe ID: 69%
- Profound ID: 64%
- NCI Average: 76%
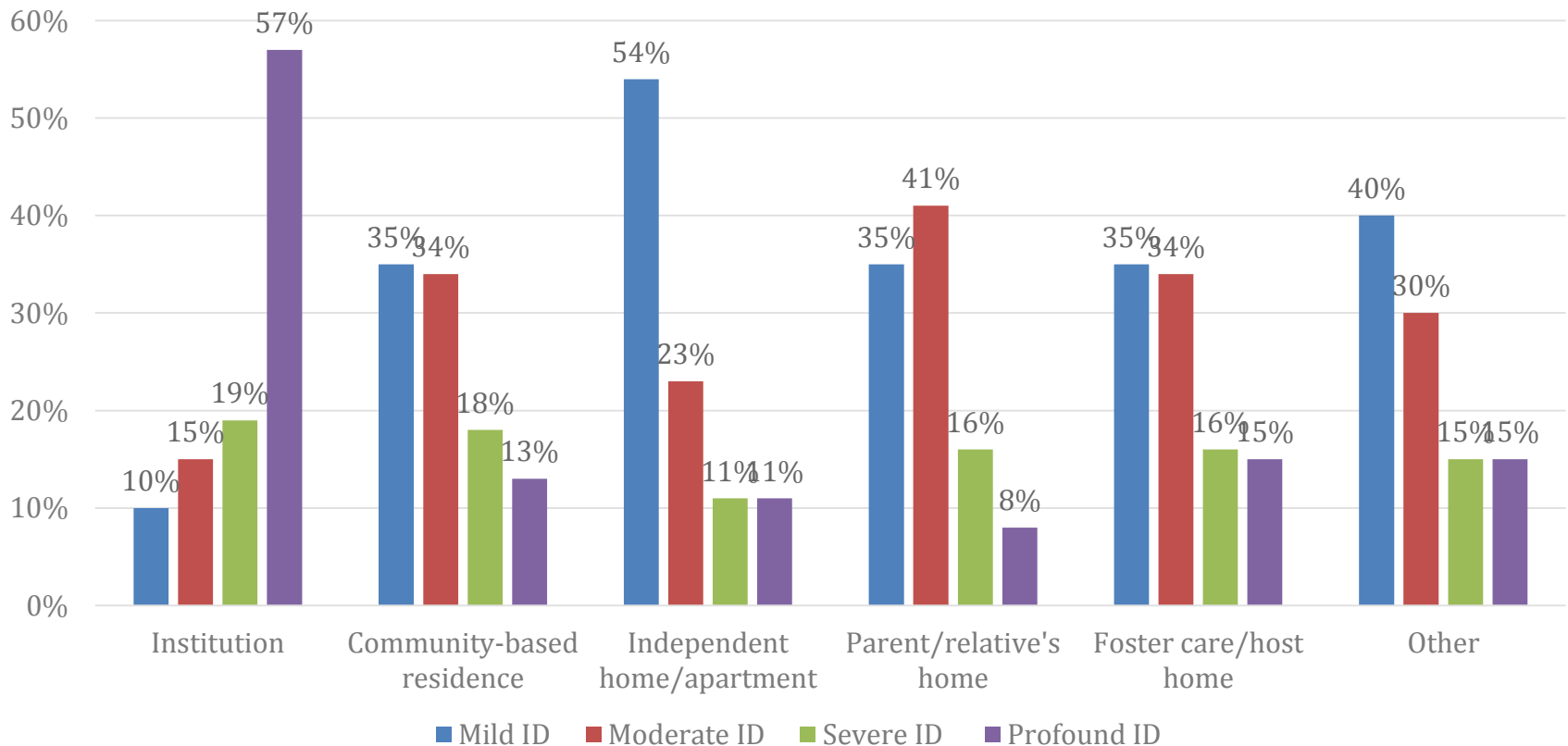
# Examples: Outcomes Vary by Level of ID

## Individual Had At Least Some Input in the Following **Choices**



Chart showing percentage by level of ID across choice categories:

| Choice | Mild ID | Moderate ID | Severe ID | Profound ID |
|---|---|---|---|---|
| Chose Home | 68% | 55% | 34% | 17% |
| Chose Roommates | 57% | 46% | 33% | 20% |
| Chose Staff | 70% | 68% | 62% | 54% |
| Chose Daily Schedule | 92% | 86% | 75% | 59% |
| Chose Freetime | 97% | 94% | 86% | 75% |
| Chose Day Activity | 72% | 64% | 48% | 31% |
| Chose What to Buy | 97% | 92% | 77% | 57% |
| Chose Case Manager | 67% | 66% | 58% | 51% |

Legend: ■ Mild ID ■ Moderate ID ■ Severe ID ■ Profound ID

National Core Indicators (NCI)
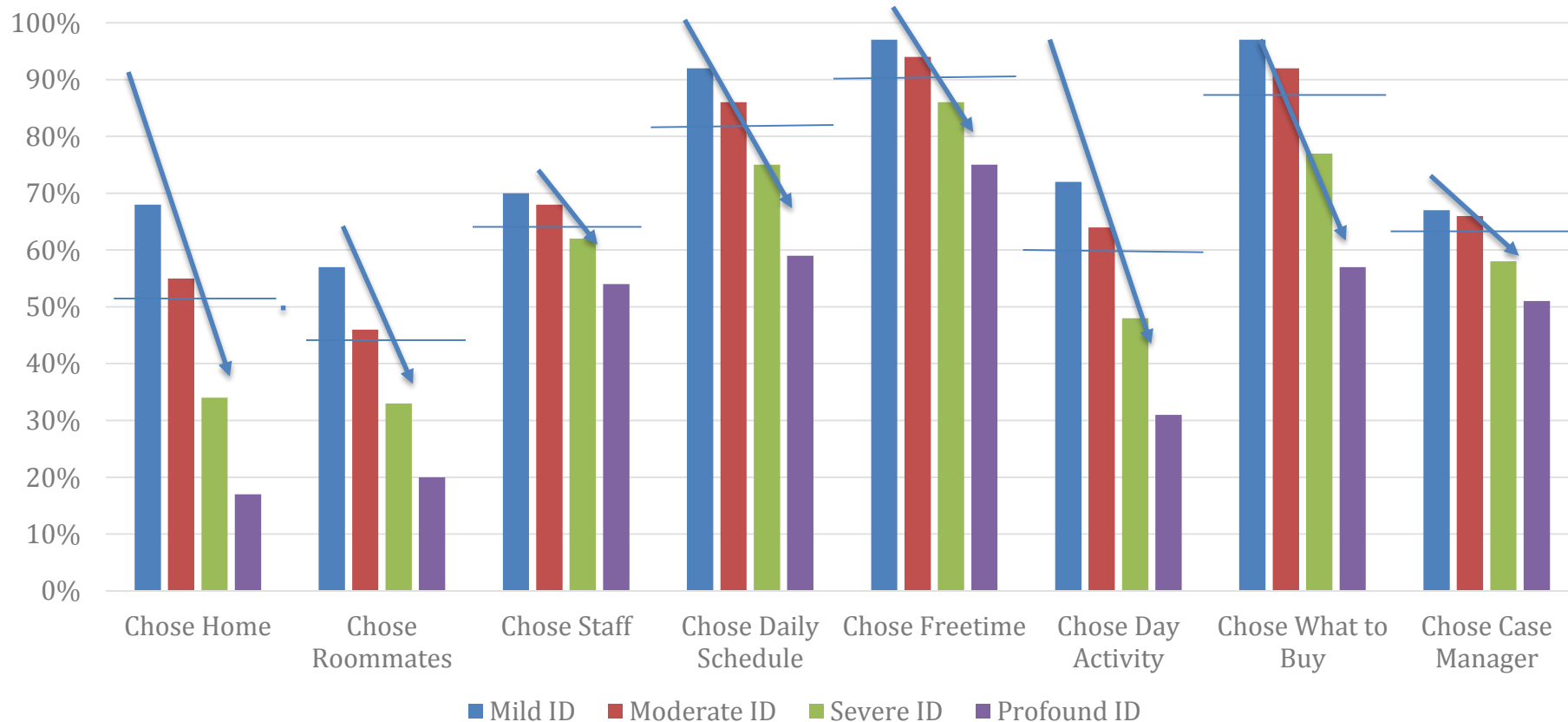
# Which indicators remain correlated through all levels of ID?

- Looked at inter-relatedness of all indicators.
  - Correlation matrix
- Identified indicators that were significantly related to other indicators
  - And significance persisted for all levels of ID
- This means that these indicators *may be* outcome predictors

# Which indicators demonstrate a high number of correlations through all levels of ID?

- Relationships:
  - Can go on date with or without restrictions
  - Has best friend
  - Can see friends when wants to
  - Has opportunities to help others
- Access & Service Coordination
  - CM/SC asks what you want
  - Always has a way to get places
  - Staff have needed training
- Choice
  - All variables
- Community Inclusion Scale

# Caveats

- This is a preliminary analysis
- Other demographic characteristics may have more of an influence on outcomes. Needs more investigation
  - Residence type
  - State of residence
  - Mobility
  - Preferred means of expression
- States are moving away from a "mild, moderate, severe, profound" measurement system towards a more functional assessment of disability.

# Why is this important?

- Indicates need for further research:
    - Focusing on outcomes for all individuals who receiving services may miss areas for improvement for segments of population

# Contacts

- Valerie Bradley: vbradley@hsri.org

- NCI website: www.nationalcoreindicators.org