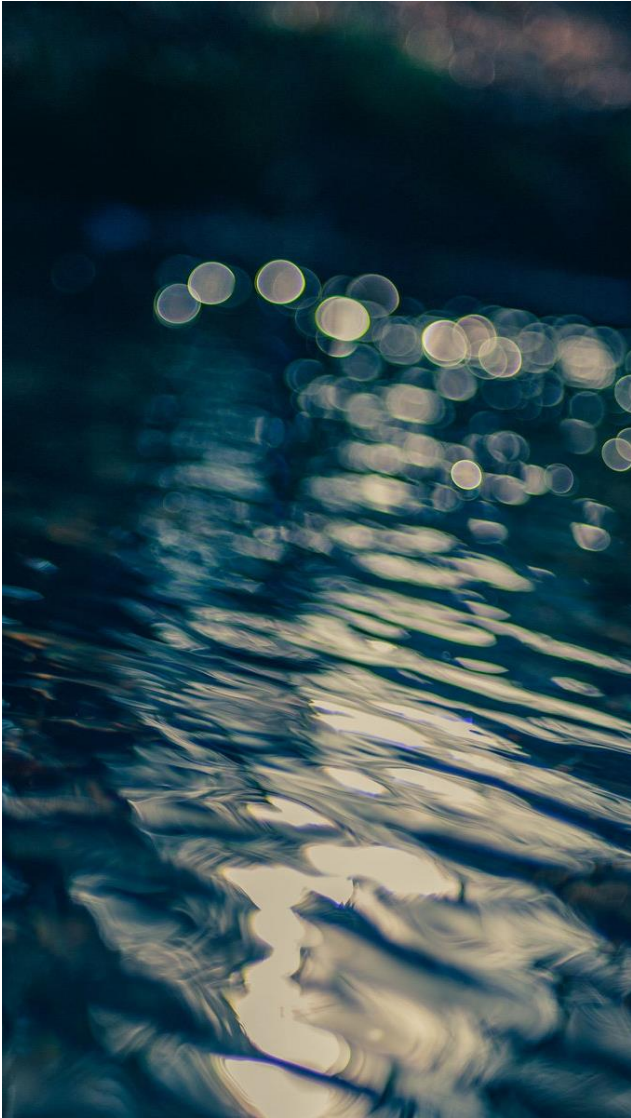




Our Field at a Crossroads

... IN THE NORTHEAST AND BEYOND

VALERIE J. BRADLEY
AAIDD REGION X
AUGUST 9, 2018



Issues and Reflections

- Who are our heroes?
- What have we accomplished?
- What challenges remain?
- Why we care about quality and the power of data
- What do we know about the quality of services and supports in the Northeast
- How are states using data
- Where do we go from here?

Some of the Heroes Who Shaped Our Field



President John Kennedy, created the President's Committee on Mental Retardation



Wolf Wolfensberger, author of *Normalization*



Elizabeth Boggs, woman behind the Developmental Disabilities Act



Katie Beckett and her mother Julie Beckett, led the way to Medicaid HCBS



Justin Dart, Co Chair of the National Council on Disability, powerful advocate for the ADA

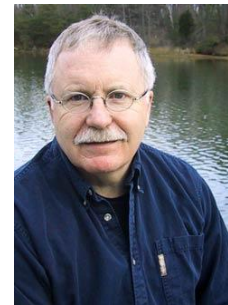


Dr. Allen Crocker, advocate, mentor and all around good human

More Heroes . . .



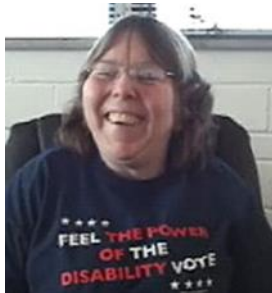
Herb Lovett, early proponent of positive behavior support



Beth Mount, Michael Smull and John O'Brien pioneers in person centered planning



Gunnar Dybwad, first Executive Director of the Arc and teacher and mentor



Nancy Ward, first chair of Self Advocates Becoming Empowered



Trajectory of Change

We have made significant strides over the past several years that we should celebrate:

Recognition of the evils of segregation and the “soft bigotry of low expectations”

Rejection of dehumanizing and degrading treatment approaches

Respect for the uniqueness of each human

Elevation of quality of life outcomes

Realization that the congregation of individuals in large distant facilities diminishes humanity and contributes to dysfunction

Embrace of the wisdom of individuals with ID/DD and their inclusion in conversations at all levels of the system

However . . .

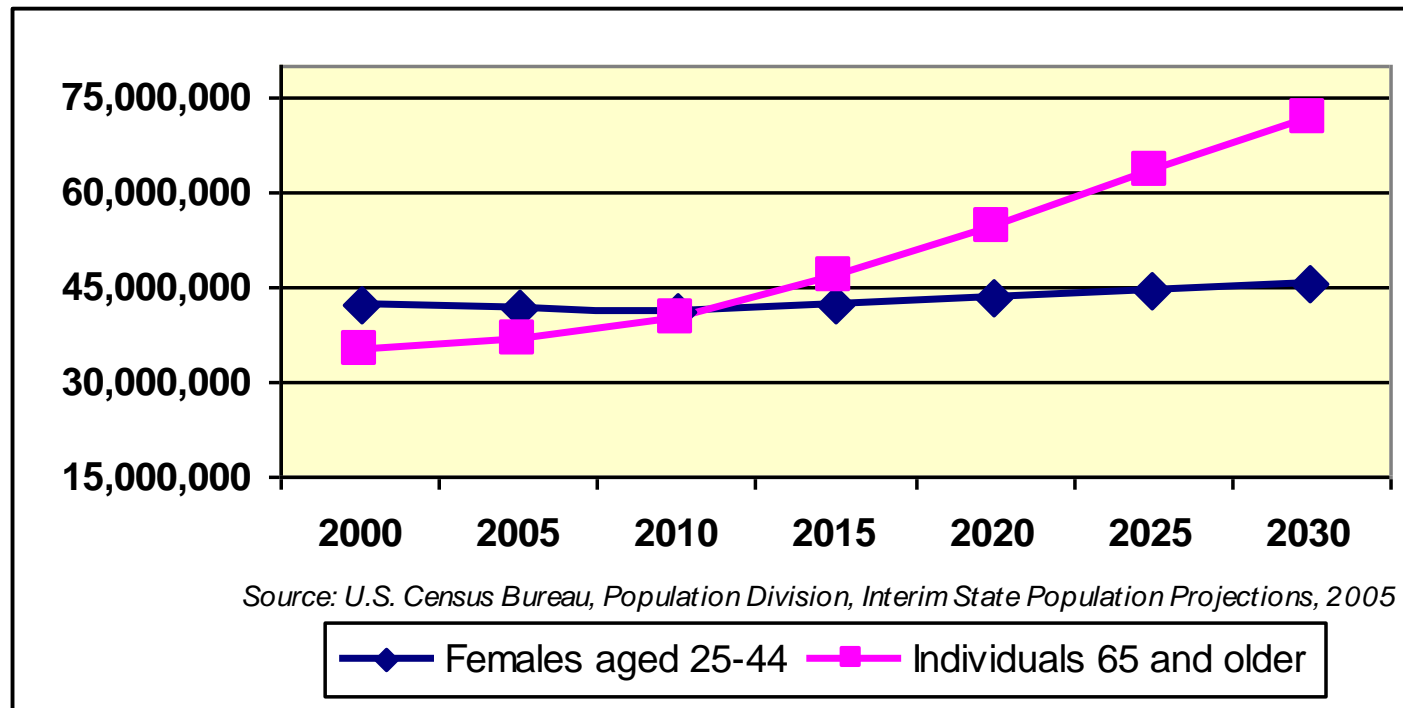


It is never wise to assume that progress is a constant unless there is an abiding commitment to make it happen. . . . Hard fought reforms can be lost in the face of complacency and self-satisfaction.

Present Challenges and Opportunities



Demographic Shift and the Impending Gap in Available Care Givers



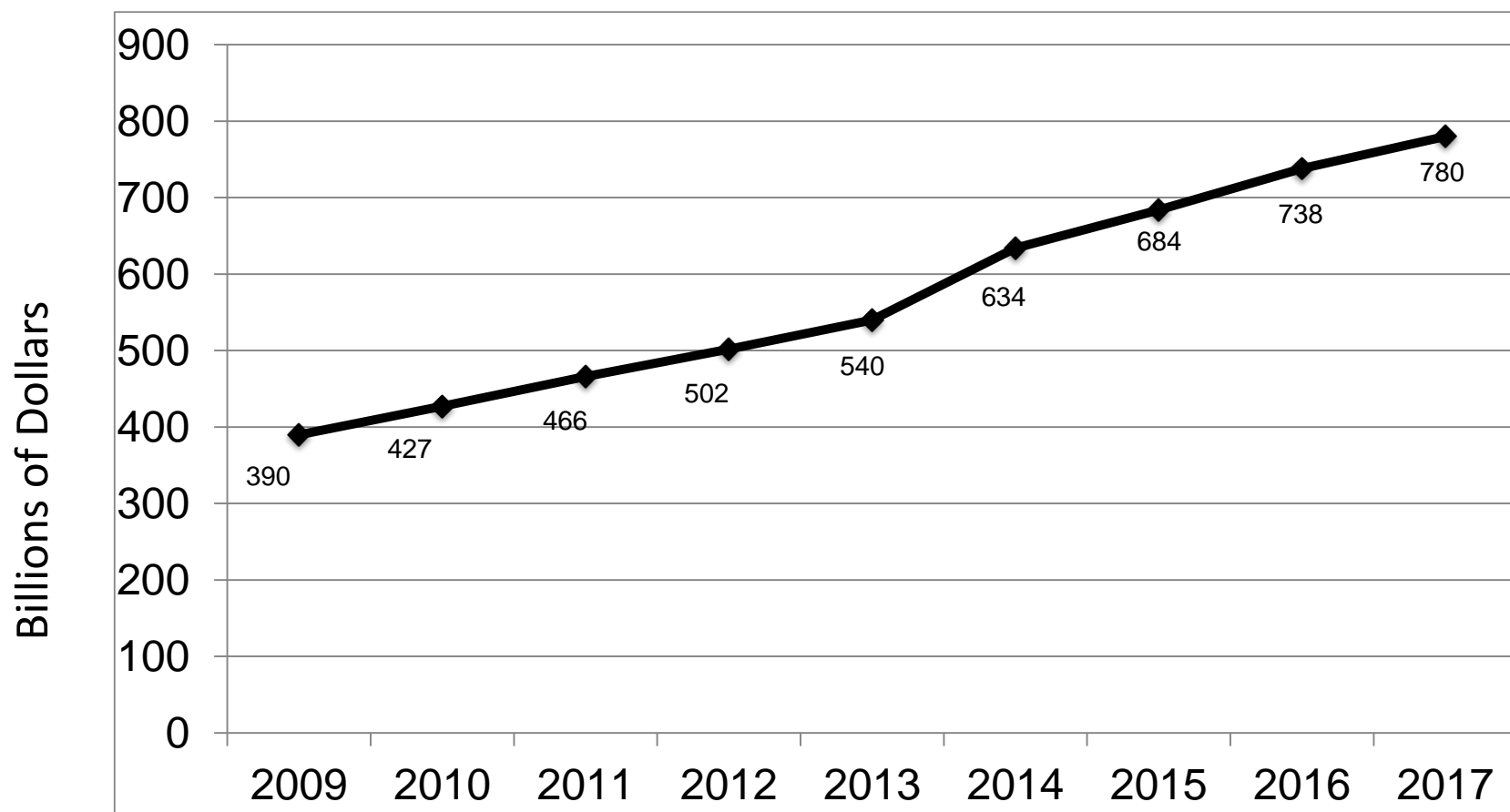
Growth in Autism Spectrum Disorder

NUMBER OF CHILDREN IDENTIFIED WITH ASD

1 IN 68



Medicaid Spending More Than Doubled Between 2009 and 2017



Source: Center for Medicare and Medicaid Services, Office of the Actuary



Shifting Medicaid Environment

Value Based Purchasing and development of quality metrics

Managed care – currently 10 states include I/DD in MLTSS

HCBS Settings rule and person centered planning requirements

Possibility of capitated funding for Medicaid and elimination of the expansion under the ACA

Broadened use of capped support waivers and cross population waivers

States are Revamping their Rate Setting and Resource Allocation Strategies

Resource Allocation – using data (individuals assessments and state cost data) to predetermine funding levels for each person

What Resource Allocation Hopes to Achieve

- Fairness
- Equity
- Predictability
- Enables Self-Direction
- Controls Costs





Changes in the Provider Environment

Aging provider leadership leading to increased retirements

Increasing demands creating exhaustion in leadership

Mergers and consolidation of agencies continue

Small agencies unable to afford the infrastructure necessary to meet accounting and other requirements from states and/or managed care

Workforce challenges and inability to spend up to allocations

Recent Surprises

The increasing power of the farmsteads and gated communities

The ferocious backlash to the Republican health care reform

Slow progress of managed care in ID/DD

Work requirements in some states for Medicaid

Persistence of the Affordable Health Care Act albeit diminished





Why Do We Care and How do We
Measure It?



Why Should We Care About Quality?

We have created a movement and made promises to people with disabilities and their families

Ideology alone does not create a stable and reliable system of supports

The greater the investment the greater the expectations

Unless we build quality in at the beginning, it is very hard to retrofit a program later



Power of Data

“The plural of anecdote is not data”

As a field, we have benefited from long term data collection including from University of MN, University of MA, the Coleman Center at the University of Colorado, and National Core Indicators (NASDDDS and HSRI)

Data contributed to the downsizing of institutions and the growth of the community system

Data on outcomes for people and families have helped to structure accreditation approaches that improved the quality of providers

Data on employment continues to strengthen our resolve to find more opportunities people with intellectual and developmental disabilities

Data on the DSP workforce is helping to raise wages

Antecedents of the Settings Rule



Normalization and the assumption that people with disabilities have the same rights to live normal lives in their communities as people without disabilities



Landmark court decisions including the Olmstead case that required that people with ID/DD be supported in the community



Wide variations in the size, quality and inclusiveness of community services

HCBS Rule: New Expectations

Purpose: Ensure people receiving federal funding for long-term services have full access to the benefits of community living and opportunities to receive services in the most integrated setting appropriate. Requires that waiver services:

Are integrated in and support full access to greater community

Ensure the person receives services in the community with the same degree of access as people not receiving federal Medicaid funding

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



HCBS: Community Services and Supports

Are chosen by the person from among residential and day options that include generic settings

Respect the participant's option to choose a private unit in a residential setting

Ensure right to privacy, dignity and respect and freedom from coercion and restraint

Optimize autonomy and independence in making life choices

Facilitate choice of services and who provides them





National Overview and State Context

NATIONAL CORE INDICATORS

Indicators



Indicators show the state of progress towards desired change

Indicators reflect our values and expectations

Indicators should be actionable measurable

NCI Indicators can be used for:

- Assessing readiness for change (demographics, staffing, current context)
- Identify areas of opportunity for quality improvement initiative (e.g. low employment outcomes)
- Monitoring outcomes of initiatives at the state or national level (at scale)

What is NCI?

NCI is a voluntary effort by public developmental disabilities agencies to measure and track their own performance.

Collaboration coordinated by HSRI and NASDDDS began in 1997

Currently 46 states and Washington D.C. represented plus 22 sub-state entities

Goals:

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



SURVEY TOOLS

*Formerly the Adult Consumer Survey (ACS)



New England States and New York Participation

Four New England states helped launch NCI:
CT, MA, RI, and VT

New England and New York membership since:

- Massachusetts 1999
- New York 2007
- New Hampshire 2009
- Connecticut 2011
- Maine 2013
- Vermont 2013
- Rhode Island 2014



Selected NCI Outcomes

2016-17

Adult Consumer Survey: How is it Administered?

Limited to individuals who receive at least one service from the IDD agency, beyond case management

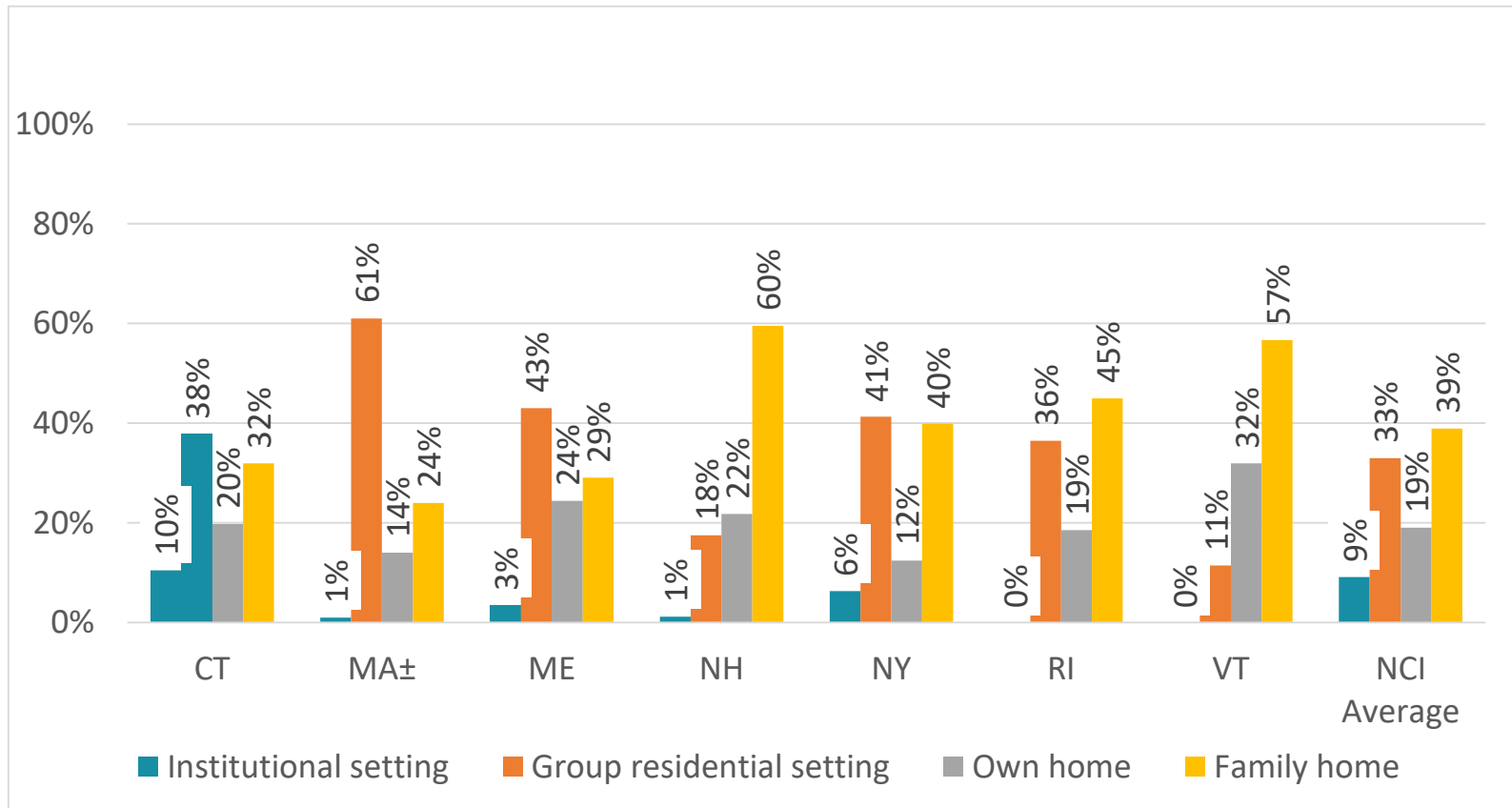
Face-to-face survey with the person receiving services

Survey includes three main parts:

- Background information – largely collected from state records (sometimes from case records, families, etc.)
- Section I – Subjective questions only the person can answer
- Section II – Objective questions can be answered by a proxy when needed

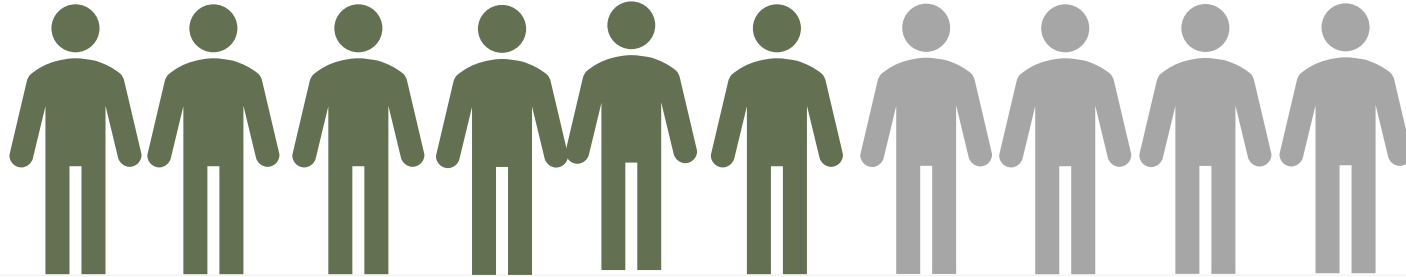


Where Do People Live?

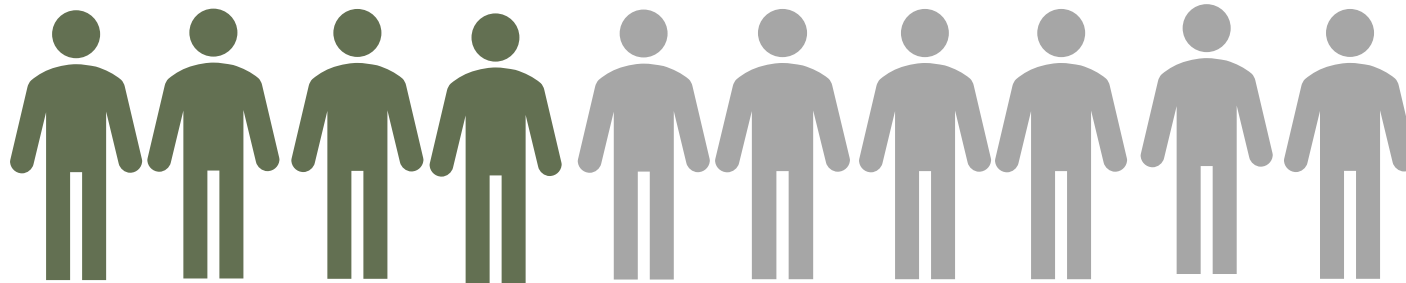


±MA data from 2015-16

People Across NCI States Living in the Family Home

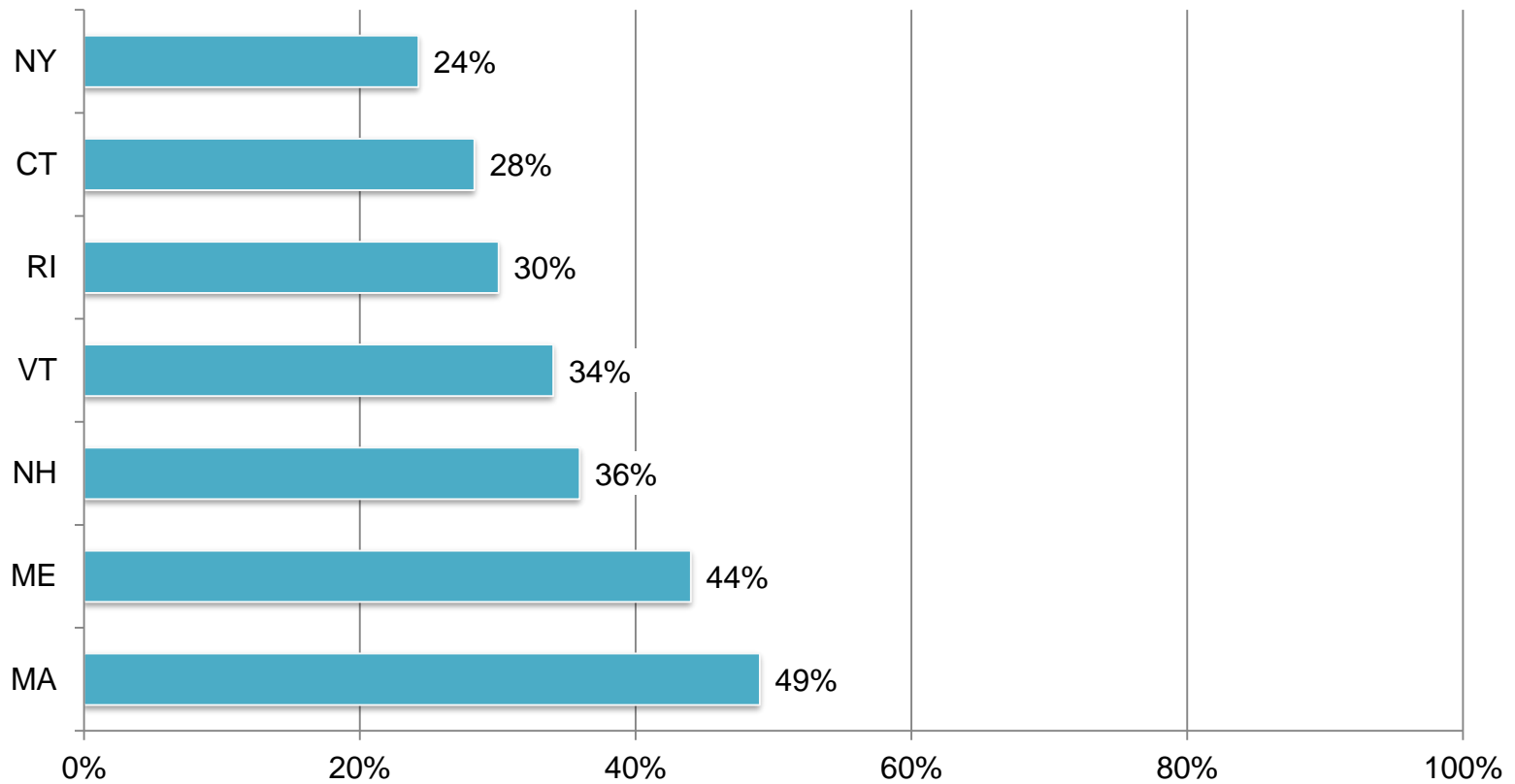


6 out of **10** people across NCI state live in the family home



4 out of **10** people 35 and older live in the family home

People 35 and Older Living in Family Home: New England and New York



Has a Community Job

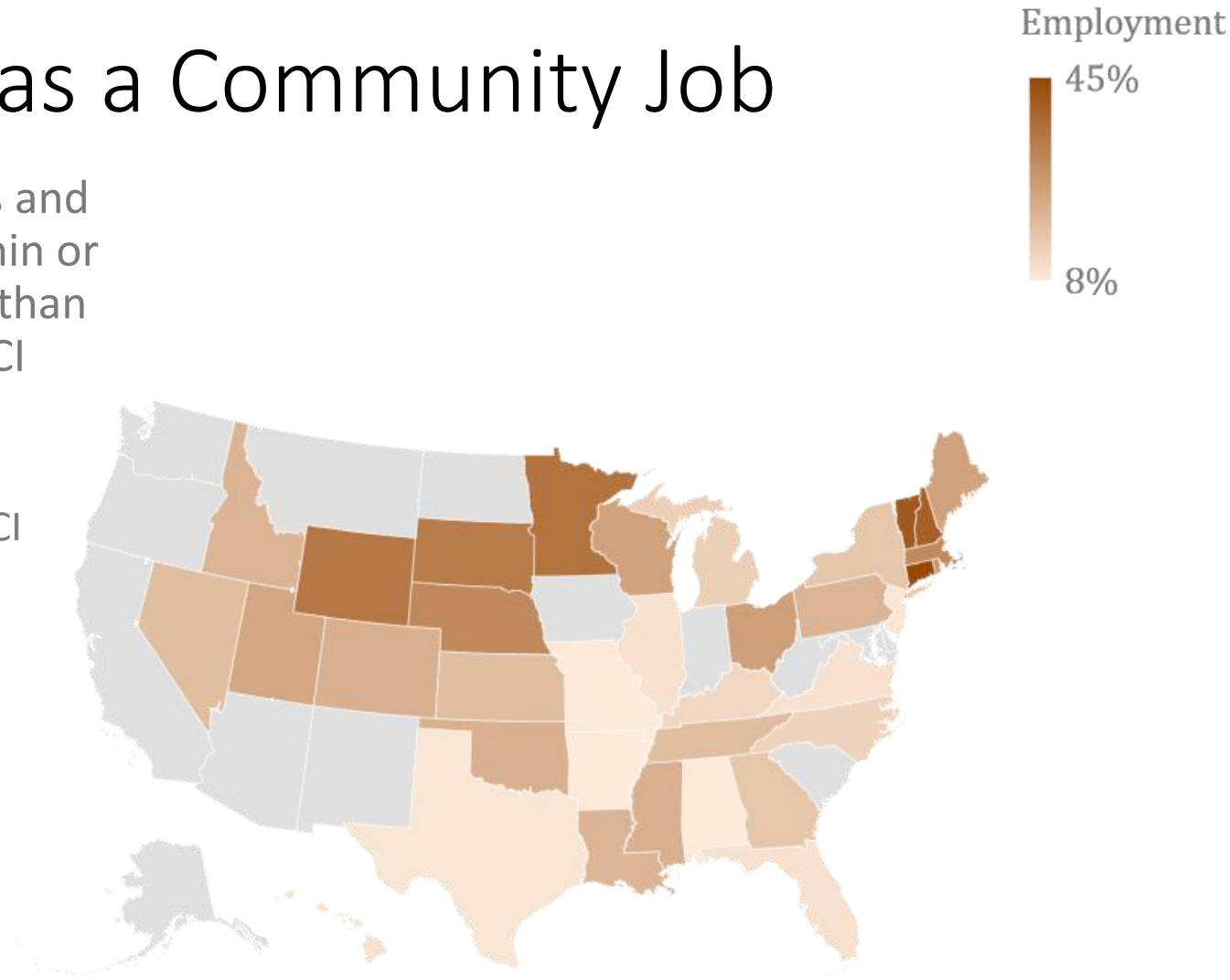
New England States and New York were within or significantly higher than the NCI Average (NCI Average 19%)

Significantly Above NCI Average

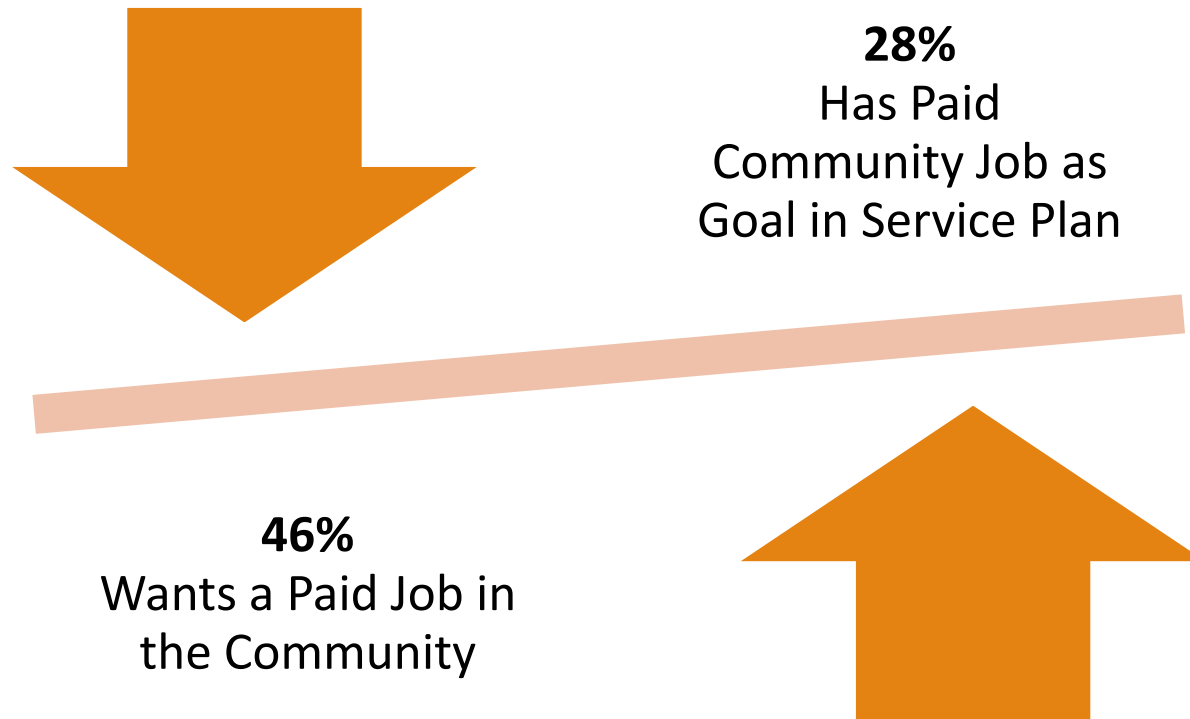
- 45% CT
- 31% VT
- 39% NH
- 30% MA±
- 27% RI

Within NCI Average

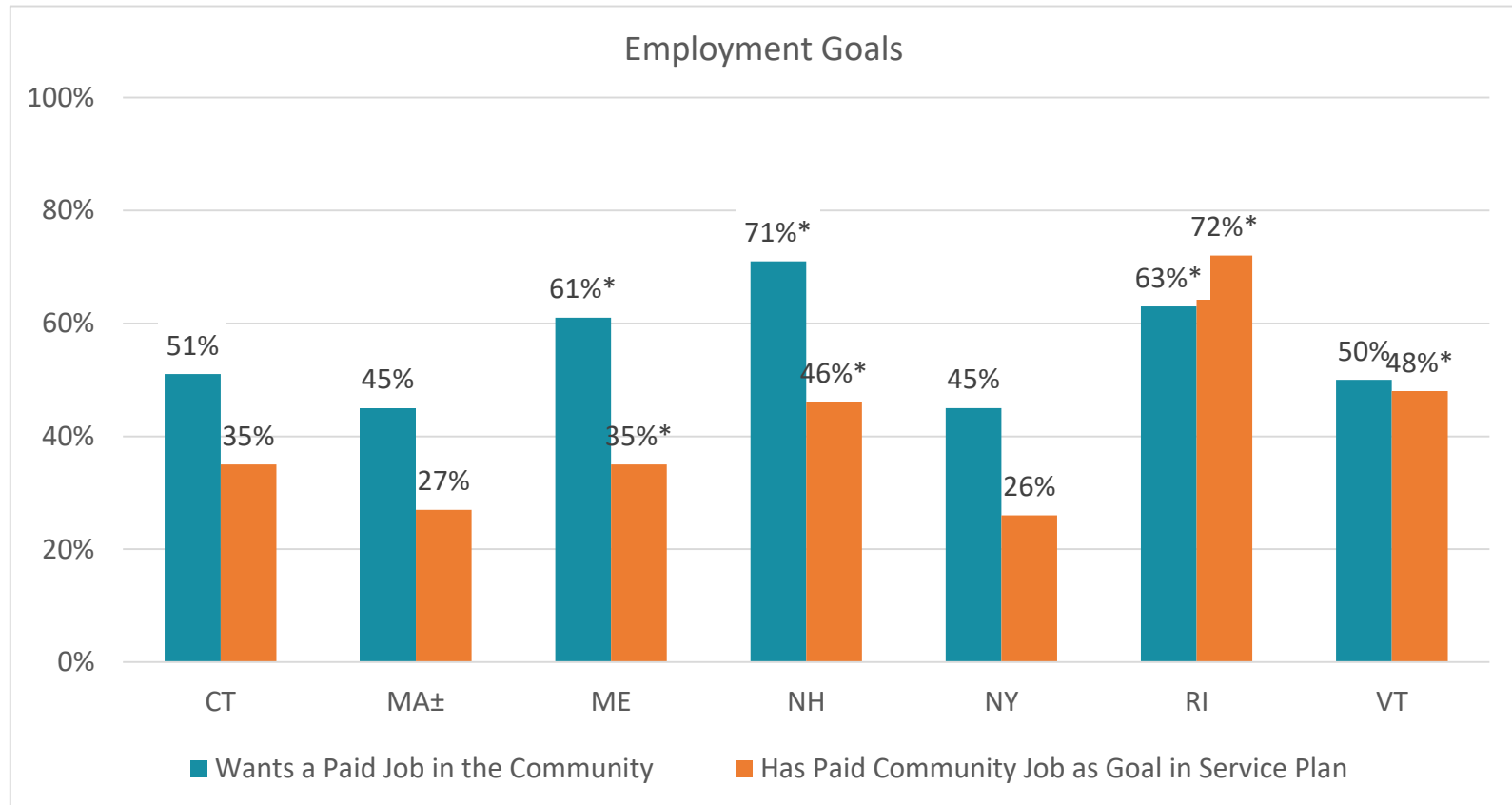
- 24% ME
- 16% NY



Employment Goals: National Data



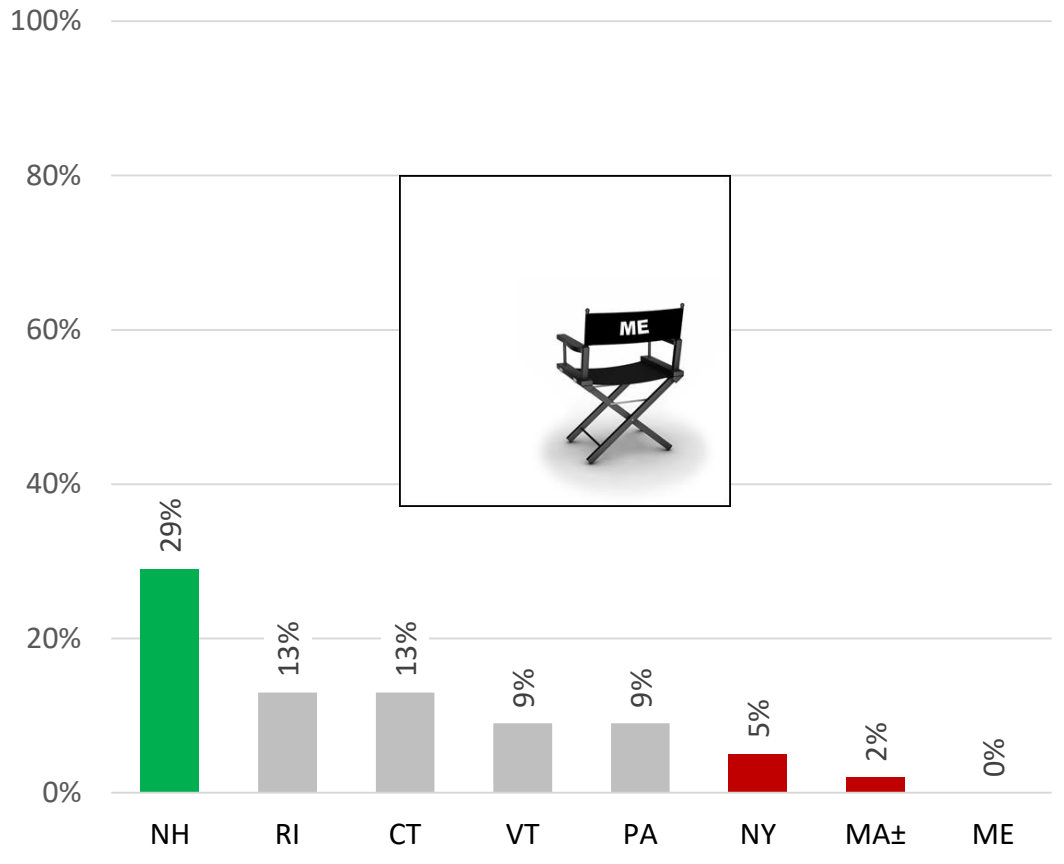
Employment Goals for Those Who Want a Job: Region X



*State was significantly higher than NCI Average

±MA data from 2015-16 (NCI Average was 47% wanted job and 30% had job as goal in service plan)

Uses Self-directed Supports Option: Region X



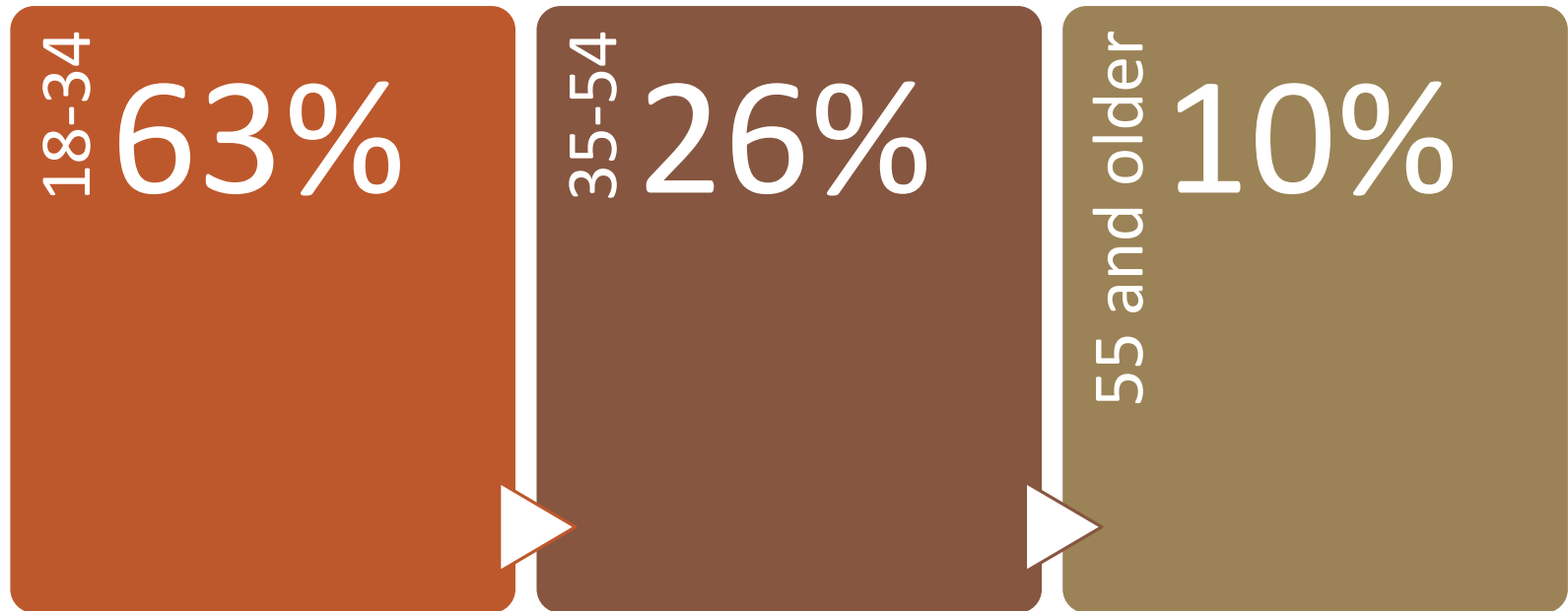
Green = State is Significantly Above NCI Average
Red = State is Significantly Below NCI Average
±MA data from 2015-16

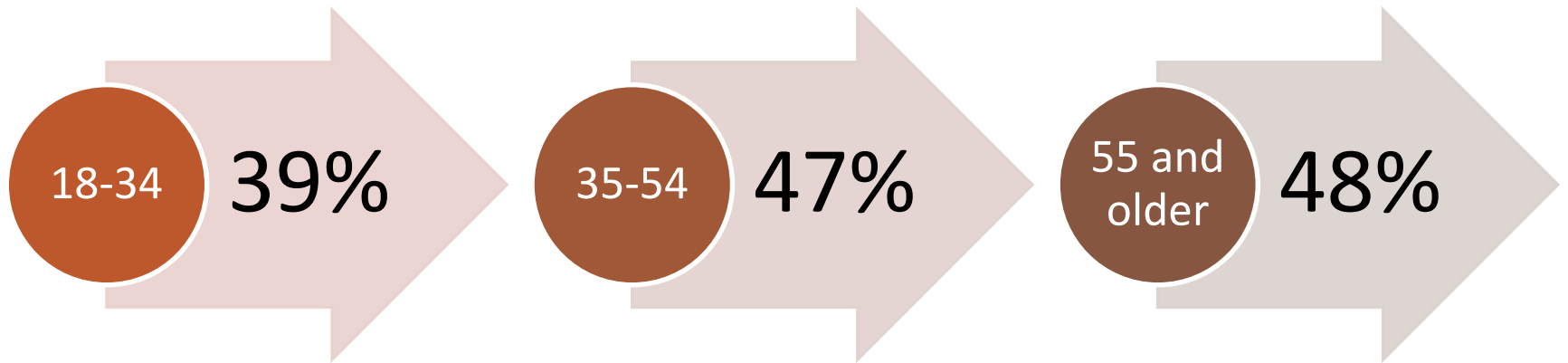
Uses Self- directed Supports Option

NCI AVERAGE: 11%

STATES RANGED
FROM 70%-0%

Self-direction and Age





Person Decides or Has Input in How Budget
for Services is Used

Community Inclusion

Went Out At Least Once in the Past Month for...				
	Shopping	Errands	Entertainment	Dining
CT	93%	94%	82%	88%
MA±	88%	91%	77%	89%
ME	94%	87%	56%	83%
NH	95%	93%	75%	91%
NY	91%	89%	70%	79%
RI	94%	93%	80%	94%
VT	90%	95%	62%	88%
NCI Average	90%	88%	77%	86%

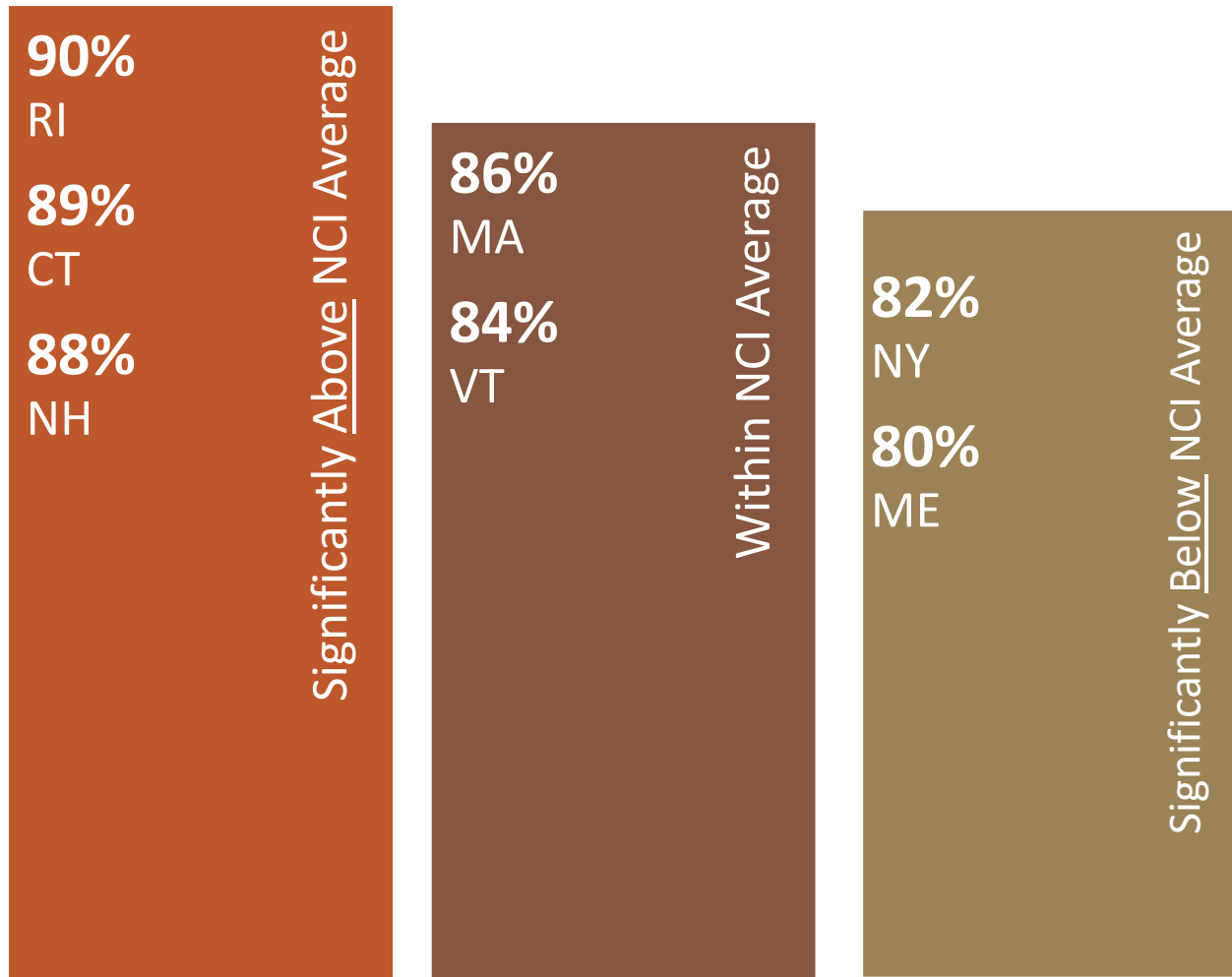
Green = State is Significantly Above NCI Average

Red = State is Significantly Below NCI Average

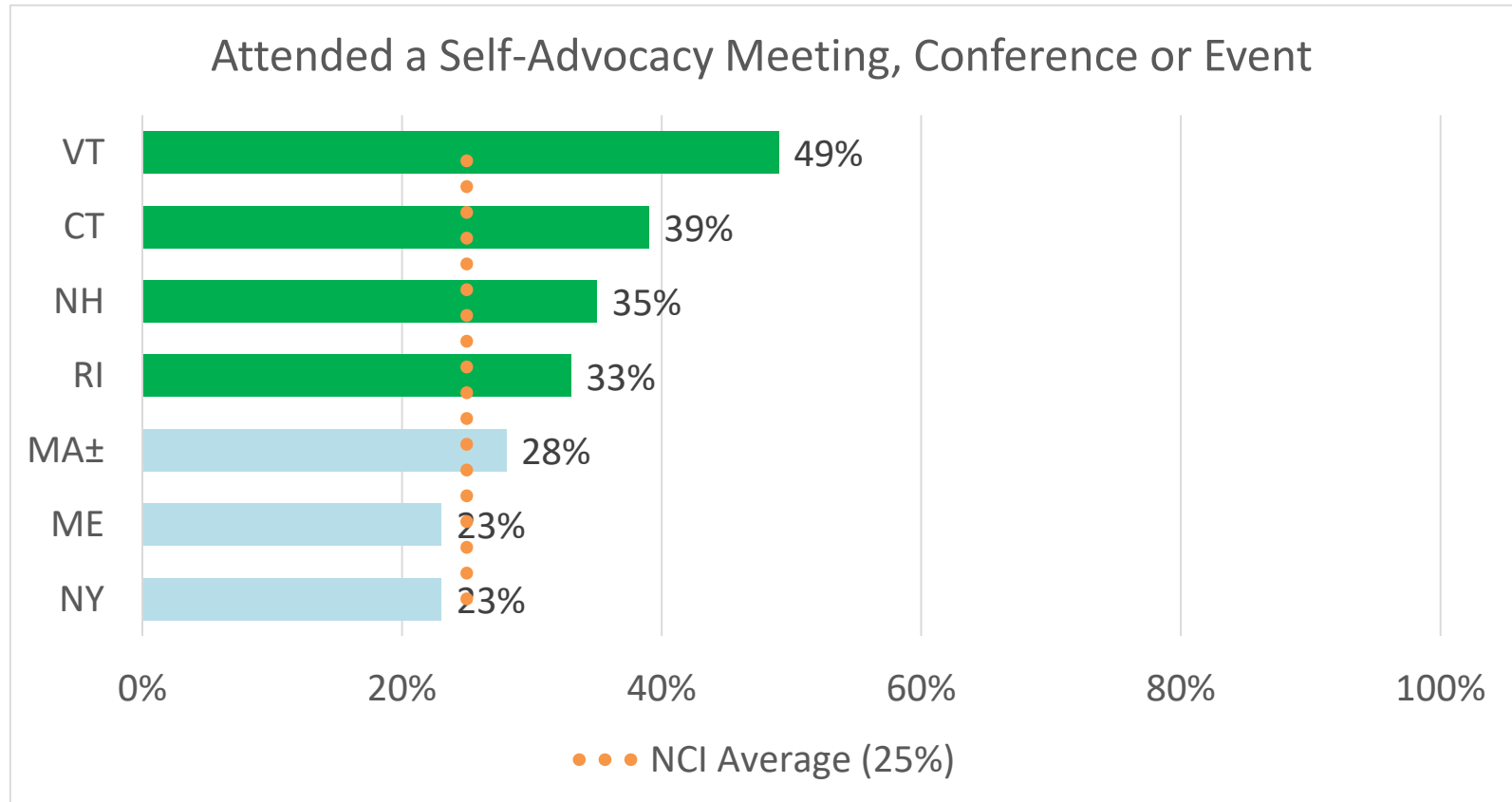
±MA data from 2015-16

Community Inclusion Scale

NCI Average: 90%

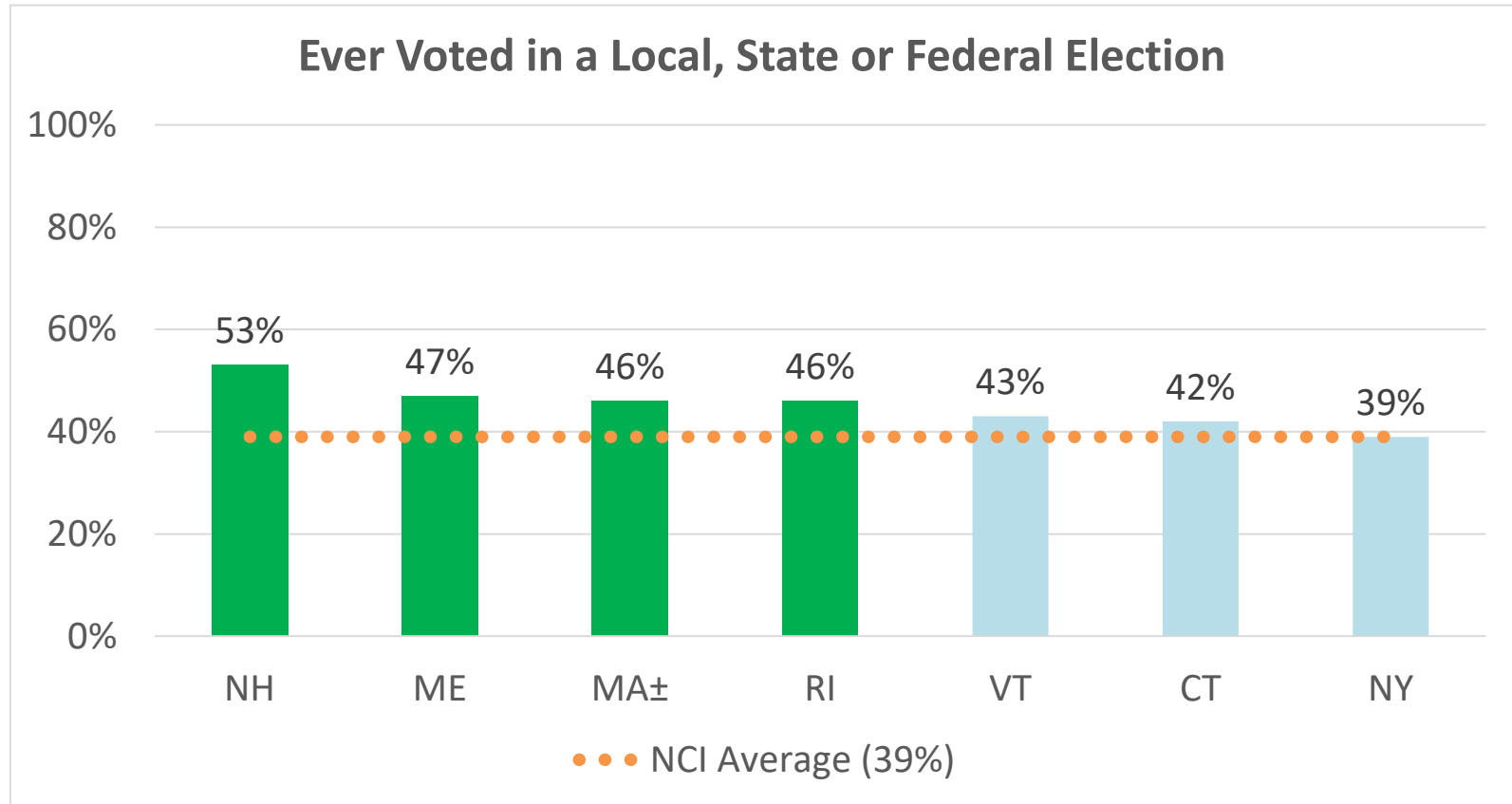


Has Attended a Self-Advocacy Meeting, Conference or Event

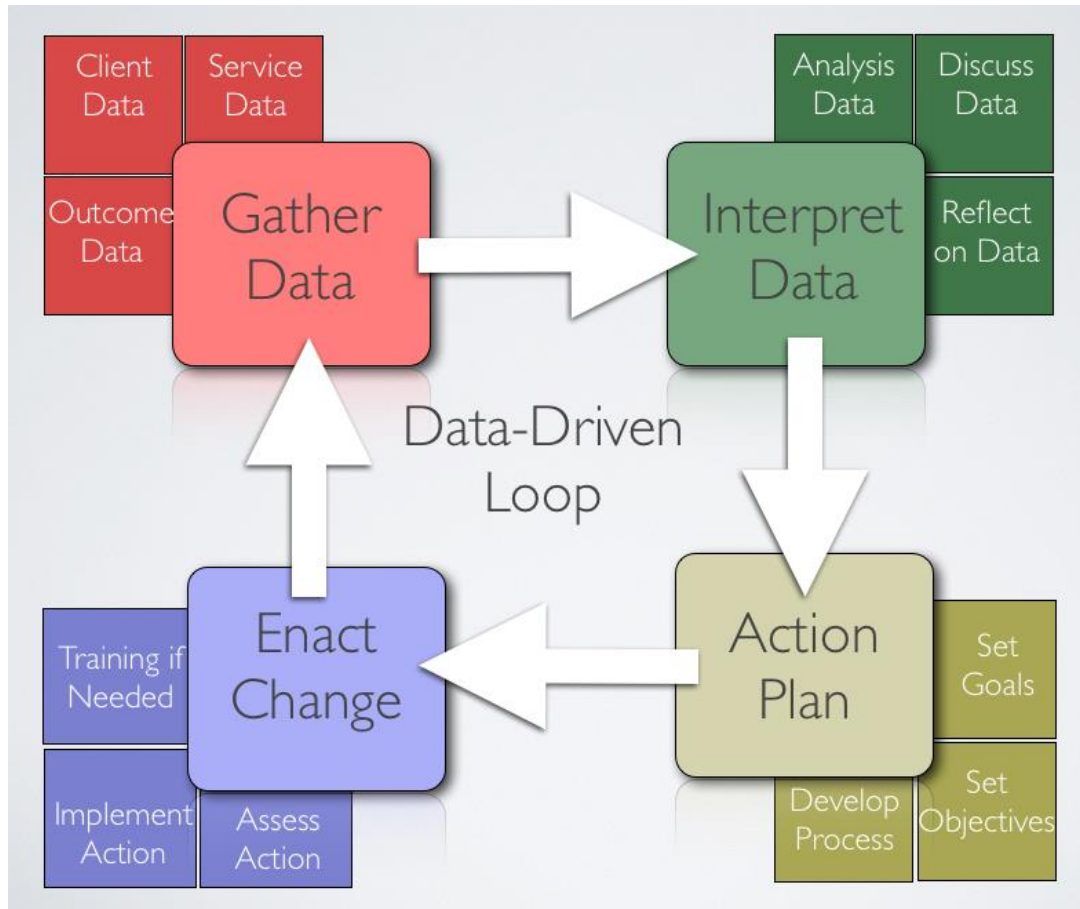


Green = State is Significantly Above NCI Average
±MA data from 2015-16 (NCI Average was 28%)

Ever Voted in a Local, State or Federal Election



Green = State is Significantly Above NCI Average
±MA data from 2015-16 (NCI Average was 39%)



How Are States Using NCI Data?

Using NCI to Strengthen Service Delivery and Quality

States use NCI data to:

- Benchmark system performance
- Compare system performance with other states and to NCI average
- Provide NCI survey findings to state and regional quality councils for review, analysis and feedback
- Identify quality concerns and prioritizing service improvement activities
- Target areas for remediation and improvement at the state and system levels in line with CMS requirements



HCBS Crosswalk

NCI Staff have prepared a publication, Practical Tools for States (Pell, 2014), to assist policy makers to monitor new CMS requirements including:

- New HCBS Requirements and NCI Data
- New HCBS Requirements and NCI Data: Quick View Tables
- Revised HCBS Assurances and Sub-assurances and NCI Performance Indicators



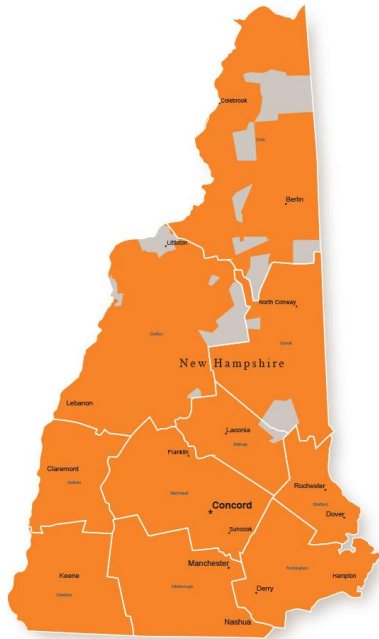
Looking Forward: 2018-19



2018-19 IPS includes additional questions about Person Centeredness including:

- Does the service plan include a goal to:
 - Create, expand, strengthen and/or maintain friendships and relationships?
 - Increase this person's participation in activities in the community?
 - Increase independence or improve functional performance in activities of daily living (ADLs)?
- Expanded service planning questions
- Satisfaction with level of community participation

New Hampshire



NH is using NCI data to support recent Living Well Grant and

NH has a legislatively mandated Quality Council with broad stake holder involvement and they request and receive a summary of NH's NCI data every two years.

They use the data to compare their results with other states as well as to look for trends in NH.

Area Agencies use NCI data to evaluate progress on their regional strategic plan

There may be additional opportunities to use the NCI information as a source of data for our redesignation process for Area Agencies.

Looking at using NCI data for waiver evidence

Connecticut



Although many individuals are working in the community, many are interested in independent employment so they funded job explorations and revised plans to help people reach those goals

Although most people wanted a paid job in the community, only 35% had an employment goal in their Individual Plan – shared information with their case managers

Advocates who work for DDS train their peers using to use NCI to tell their stories. They conduct NCI interviews and inform every participant of their rights, share resources, and offer their services as an “IP Buddy” to help with the individual planning process.

Based on NCI housing data, they have strengthened their ties with Department of Housing and stressed the need for alternative models of housing with supports;

We learned how important relationships are to individuals, and have worked in partnership with the advocacy community to develop a Healthy Relationships policy to support individuals in making informed choices in engaging in relationships.

While there were many other influencers that led to the above accomplishments, NCI has helped drive the change. NCI helps us know how we are doing, but also is a tool to keep us on course and find new direction. --



Vermont: Uses NCI data for annual reporting, performance measures in their master grants with their provider agencies, and for system development and planning.



Maine: Planning on preparing a 3 year comparative report using NCI state data; used NCI data to track compliance with Olmstead Plan



Massachusetts: Uses data with their Quality Council to create benchmarks for system improvement priorities:

Self-Advocacy/Self-Determination
Friendship/Recreation
Transportation
Employment
Community inclusion



New York: Developing approach to using NCI to monitor new Coordinated Care Organizations

Other NE States



FINAL
THOUGHTS!

FOCUS ON SYSTEM SUSTAINABILITY: WHAT SHOULD YOU ASK OURSELVES?

Are you giving value for our \$\$\$? Are you providing services with proven outcomes?

Are you providing services that people want?

Are you being good stewards of the public funds?

Are you staying in touch with the voices of self-advocates and people with lived experience?

Are you using data wisely?

Are you supporting self-direction

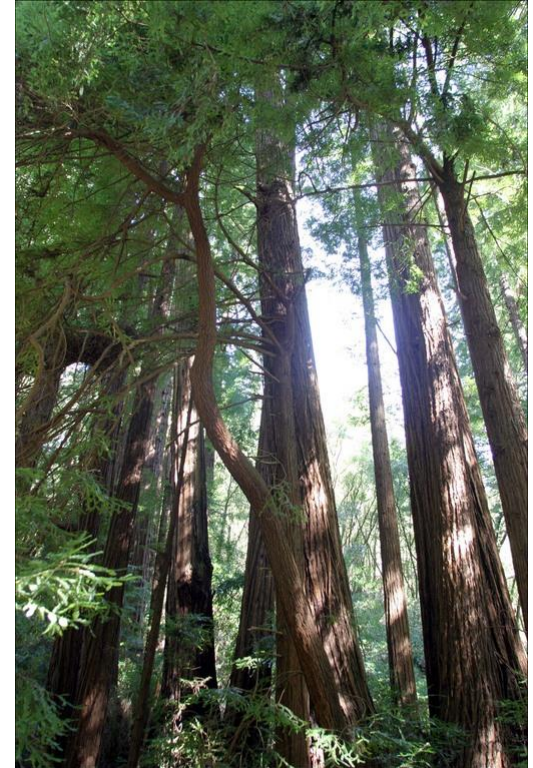
As Experience Changes, Values Must Endure

The humanity of each person

The uniqueness of their gifts

The importance of individually tailored supports, and

The importance of choice and self determination



THE END

What did she
say?

