



Maine Developmental Disabilities Council

Who We Are

The Maine Developmental Disabilities Council (MDDC) is a partnership of people with disabilities, their families, and agencies which identifies barriers to community inclusion, self determination, and independence. The Council acts to effect positive change through advocacy, training, demonstration projects, and support for other inclusive and collaborative systemic change activities.

Our Mission & Purpose

The purpose of the Council, as required under the federal Developmental Disabilities Assistance and Bill of Rights Act of 2000, is to ensure that individuals with developmental disabilities and their families participate in the design of, and have access to needed community services, individualized supports, and other forms of assistance that promote self determination, independence, productivity, integration, and inclusion in all facets of family and community life.

MDDC is committed to creating a Maine in which all people are valued and respected because we believe communities are stronger when everyone is included.



NCI-MAINE



<http://www.nationalcoreindicators.org>

Because data doesn't care what you believe.



<http://www.nationalcoreindicators.org>



What is NCI?



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

Collaboration began in 1997

45 states plus Washington DC participate

Coordinated by HSRI and NASDDDS

NASDDDS



Human Services
Research Institute



What is an “Indicator”?



Indicators are standard measures used across states to assess the outcomes of services provided to individuals and families. Indicators address key areas of concern including employment, rights, service planning, community inclusion, choice, and health and safety.



NCI Goals



- o Establish a nationally recognized set of performance and outcome indicators for DD service systems
- o Develop reliable data collection methods & tools
- o Report state comparisons and national benchmarks of system-level performance



NCI- Maine Goals

- Obtain direct feedback from service recipients
- Connect indicators to other initiatives
- Utilize reliable data to
 - Measure user satisfaction with services
 - Identify areas for quality improvement
 - Support the evolution of the service system



NCI-Maine History



Through 2010

- “Quality of Life” Survey was administered to Section 21 Waiver recipients
- Interviewers were primarily agency staff
- Project overseen by the (former) Office of Quality Improvement



NCI-Maine History



2013-

- OADS received a federal grant to resume participation in NCI
- Contracted with Maine Developmental Disabilities Council
- Interviews completed in 2014-2019
- Scheduling for 2020 has begun



NCI “Adult Consumer Survey”



- Uses conversations with adults receiving services to get information about their experiences
- Keyed to important person-centered outcomes
- Measures system-level indicators related to:
 - Employment, choice, relationships, case management, inclusion, health



o Information Gathered is Confidential

- Only participation is tracked
- Participants are identified in the database only with a code
- After the information is entered, paperwork is shredded



Why participate?



- o Participation can help other people
 - OADS learns about how well services are meeting people's needs
 - OADS learns about what people like and don't like about services
 - Maine learns about how well it is doing compared to the rest of the country



- Reliable & valid for people with all levels of ID
- Provides objective data (which we don't have much of!)
- Random sample
- Not sensitive to nuances of service systems
- Not sensitive to the nuances of people's lives



What we learned form the process

- oParticipants seemed to enjoy the interview process
- oPeople did not always say what we expected them to say



Interviewer feedback

- 🧑‍🦧 It was a privilege to spend some time with people with so many different life experiences
- 🧑‍🦧 Those who live most independently seemed the happiest
- 🧑‍🦧 Integrated employment seems to contribute strongly to happiness, well-being & self determination.



Interviewer feedback

- People do not seem to have many choices about where & how they spend their days
- People who have had behavior problems in the past said that nobody lets them forget and rules just don't relax, even when their behavior has improved.
- People often had a difficult time answering questions about living, working, doing something else or somewhere else, and about services needed- lack of awareness that there ARE other options



<http://www.nationalcoreindicators.org/states/ME/>

- Choice and Decision Making
- Self Determination
- Community Inclusion
- Relationships
- Satisfaction
- Service Coordination
- Work
- Access
- Health
- Medications
- Wellness
- Respect and Rights
- Safety

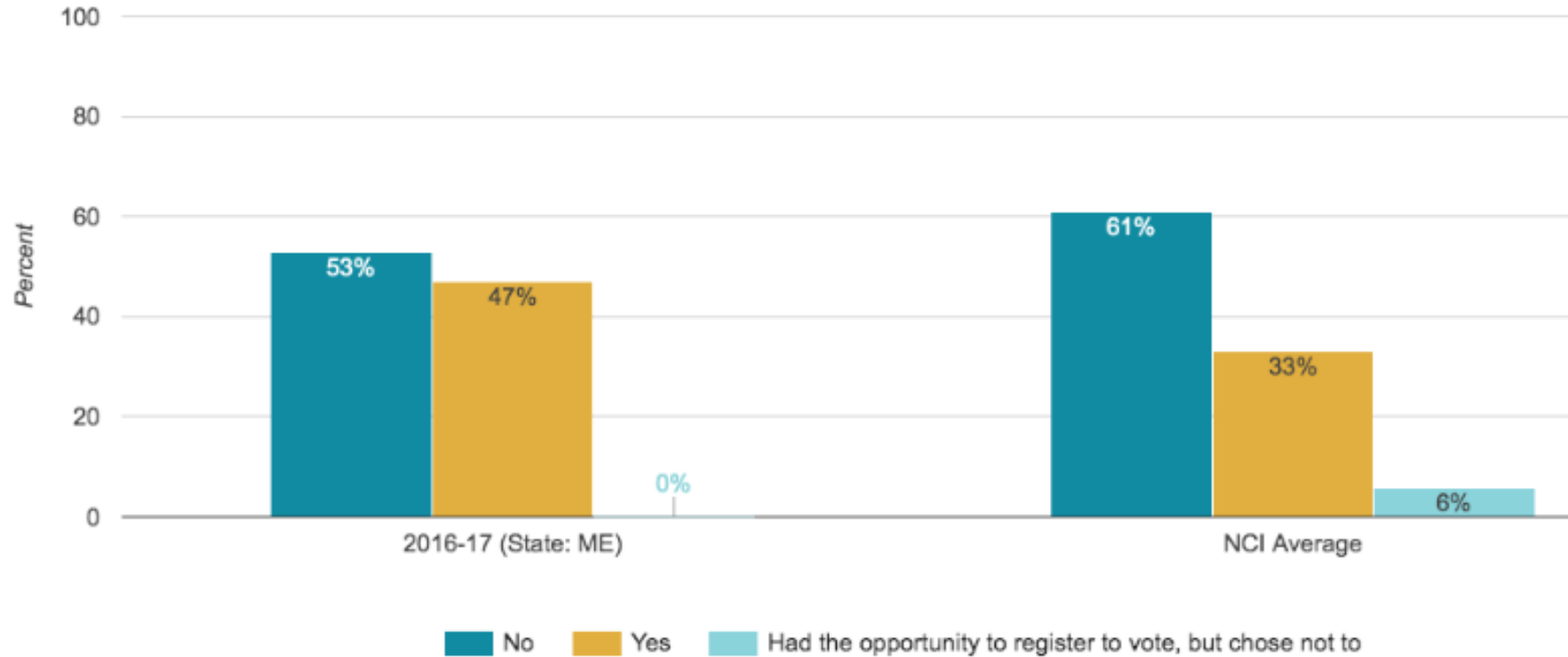


Survey Results

<https://www.nationalcoreindicators.org/states/ME/report/2016-17/>



Key Survey Results



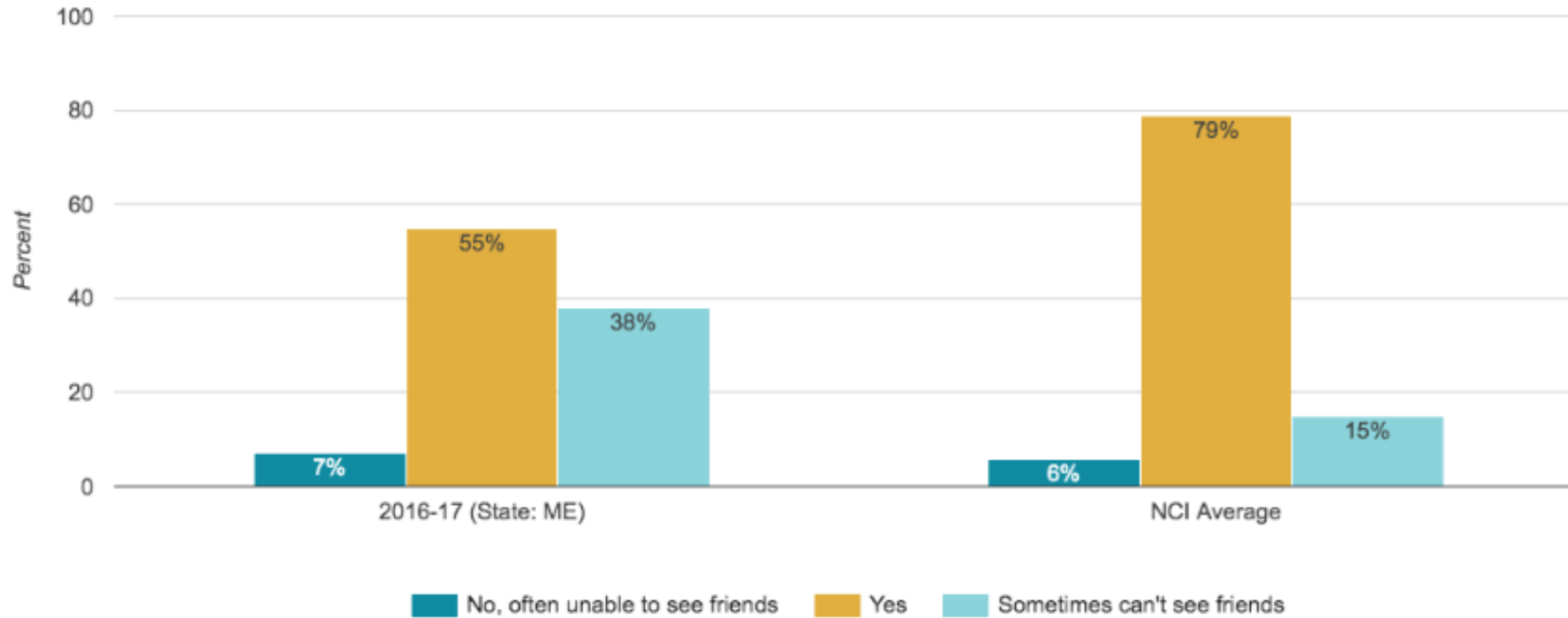
Has Voted

Proportion of people who report having ever voted in a local, state or federal election

State N = 370 | NCI N = 19448



Key Survey Results



Can See Friends

Proportion of people who reported they have friends (may be staff or family) and the support needed to see their friends when they want to

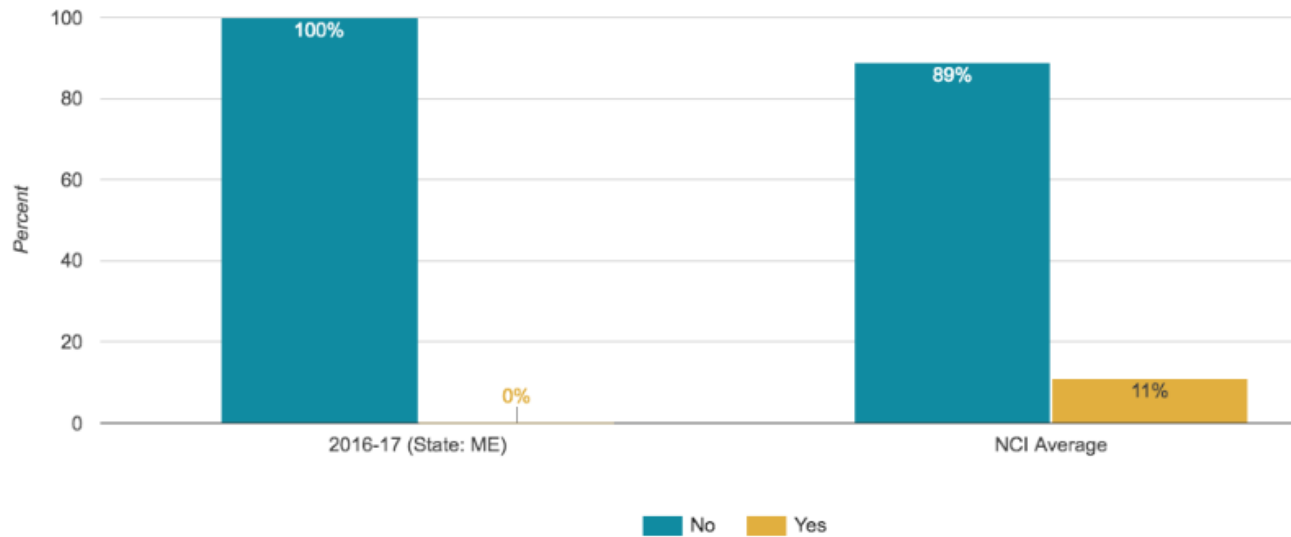
State N = 256 | NCI N = 12632



Key Survey Results

Self-Determination

People have authority and are supported to direct and manage their own services.



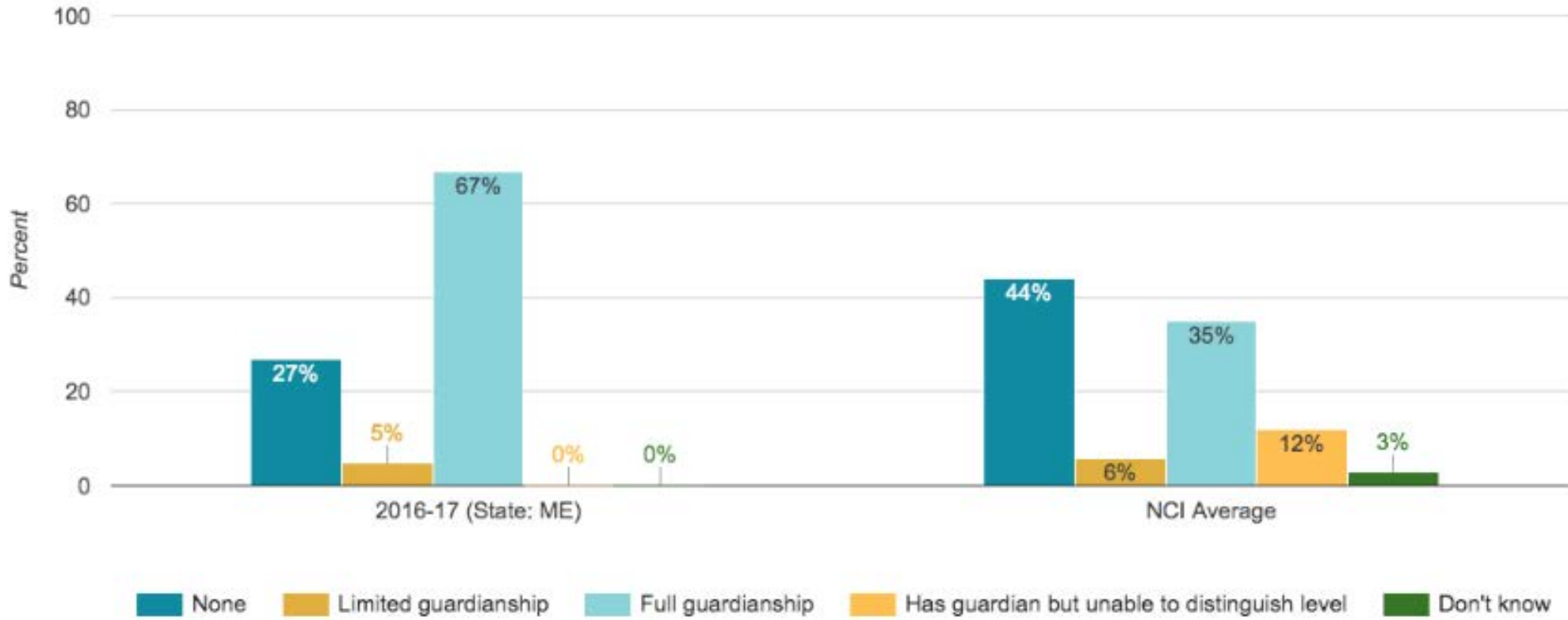
Uses Self-Directed Supports Option

Proportion of people who were reported to be using a self-directed supports option

State N = 388 | NCI N = 20346



Key Survey Results

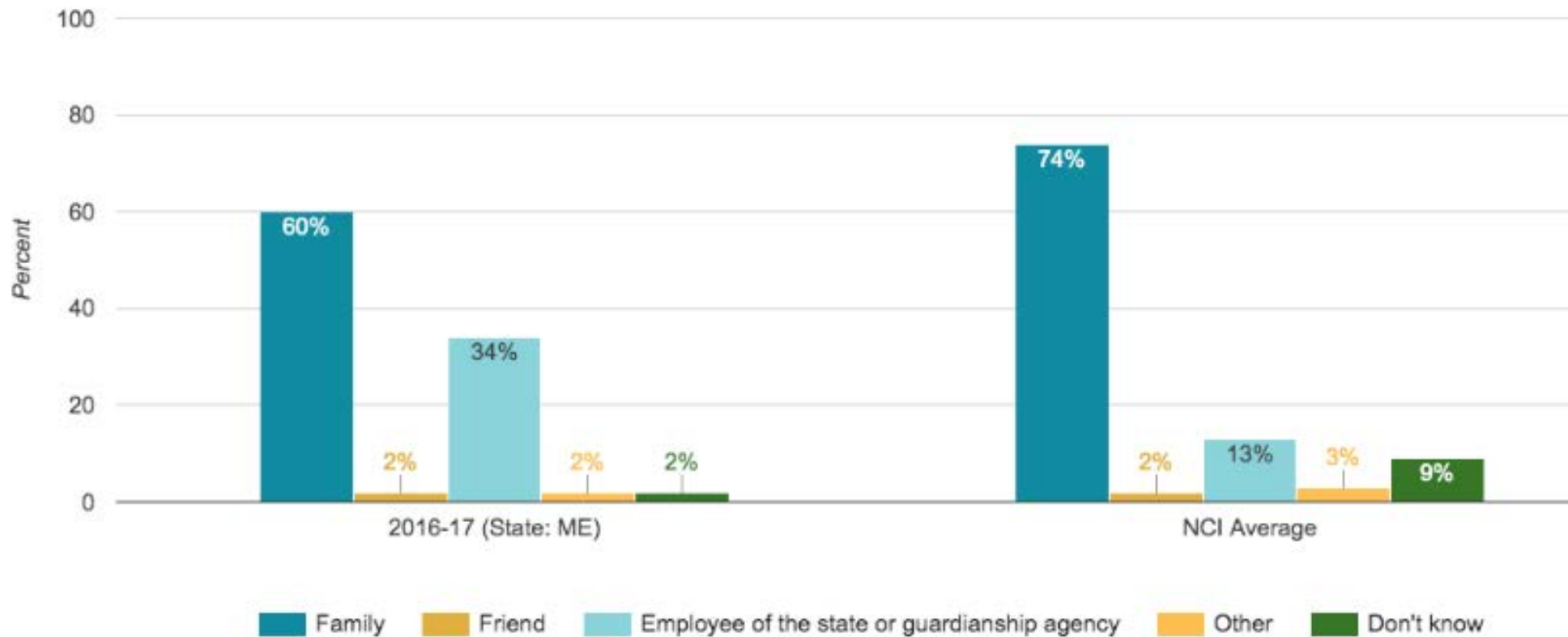


Guardianship

State N = 395 | NCI N = 21396



Key Survey Results

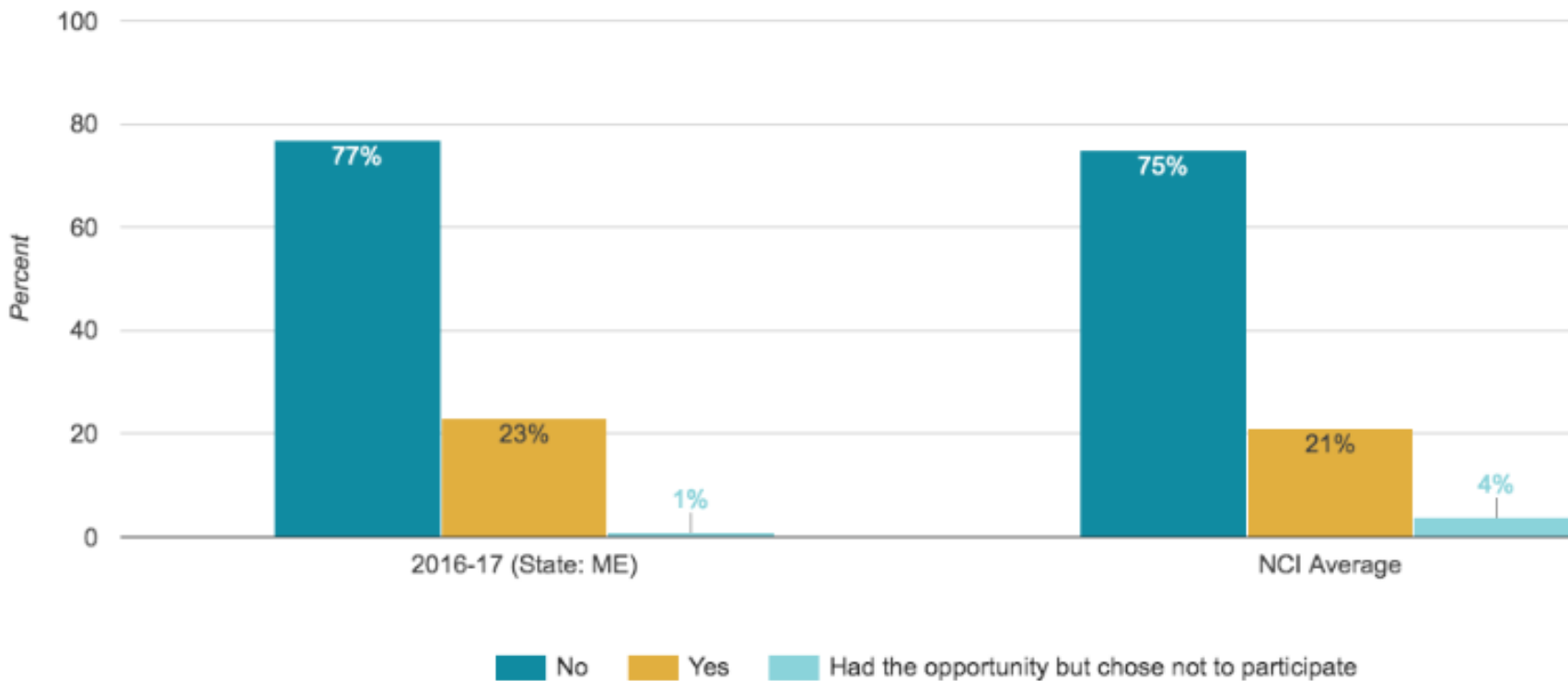


Relationship of Guardian to Individual

State N = 286 | NCI N = 11948



Key Survey Results

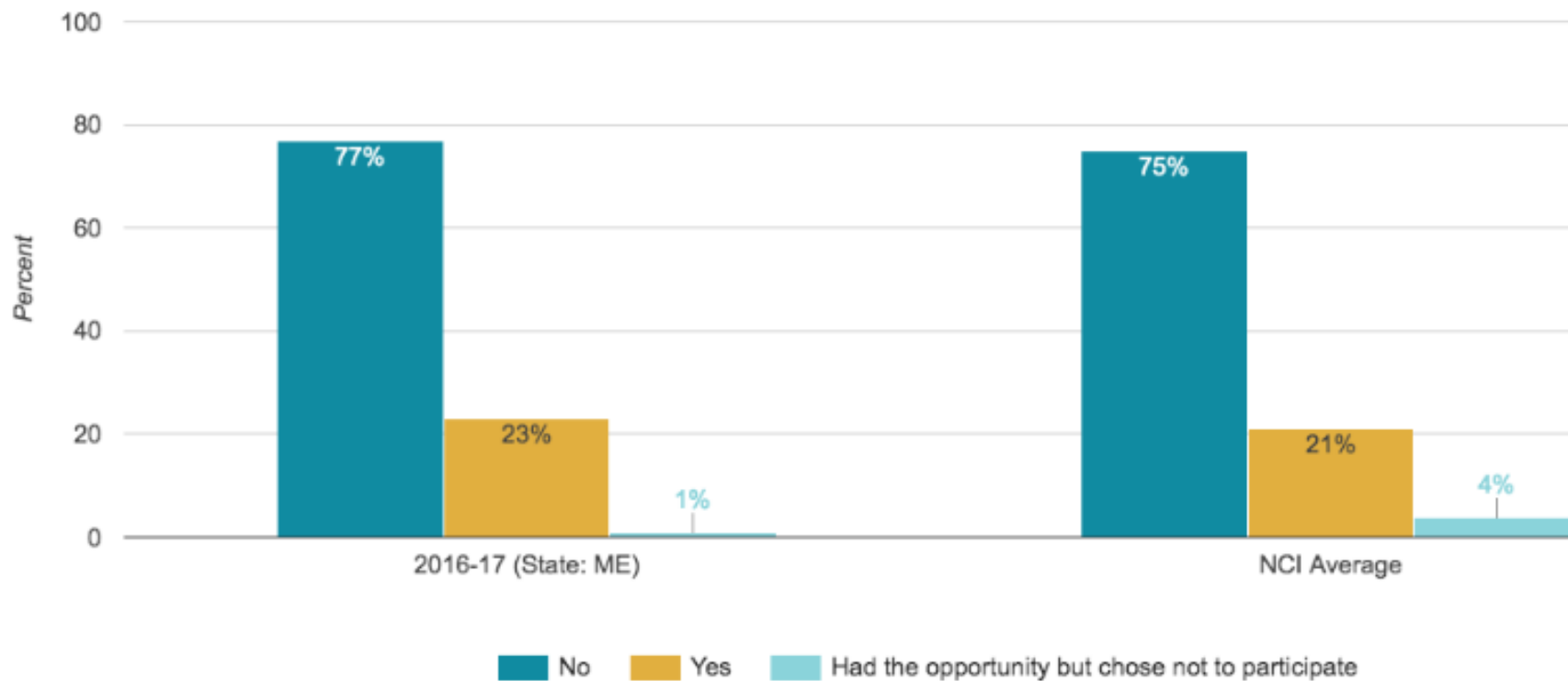


Participated in a Self-Advocacy Meeting, Conference, or Event

Proportion of people who reported they have attended a self advocacy event, or chose not to
State N = 353 | NCI N = 17176



Key Survey Results

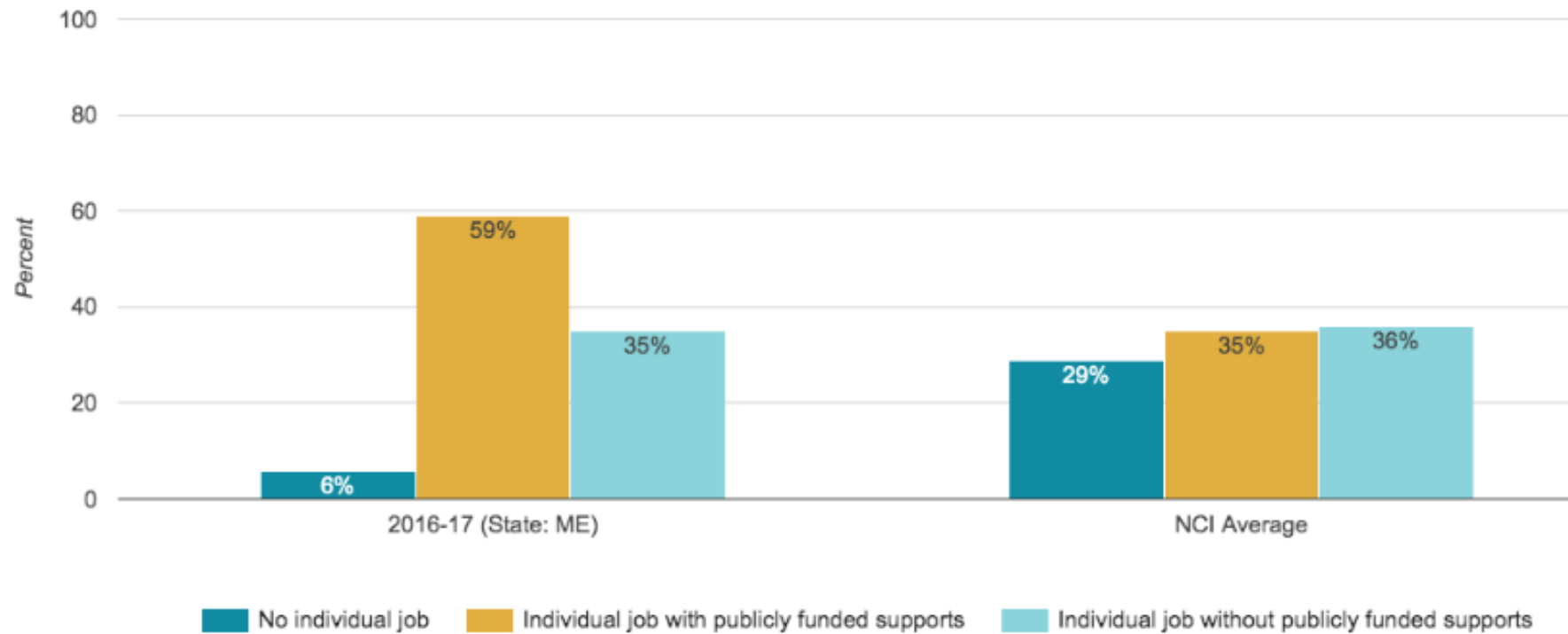


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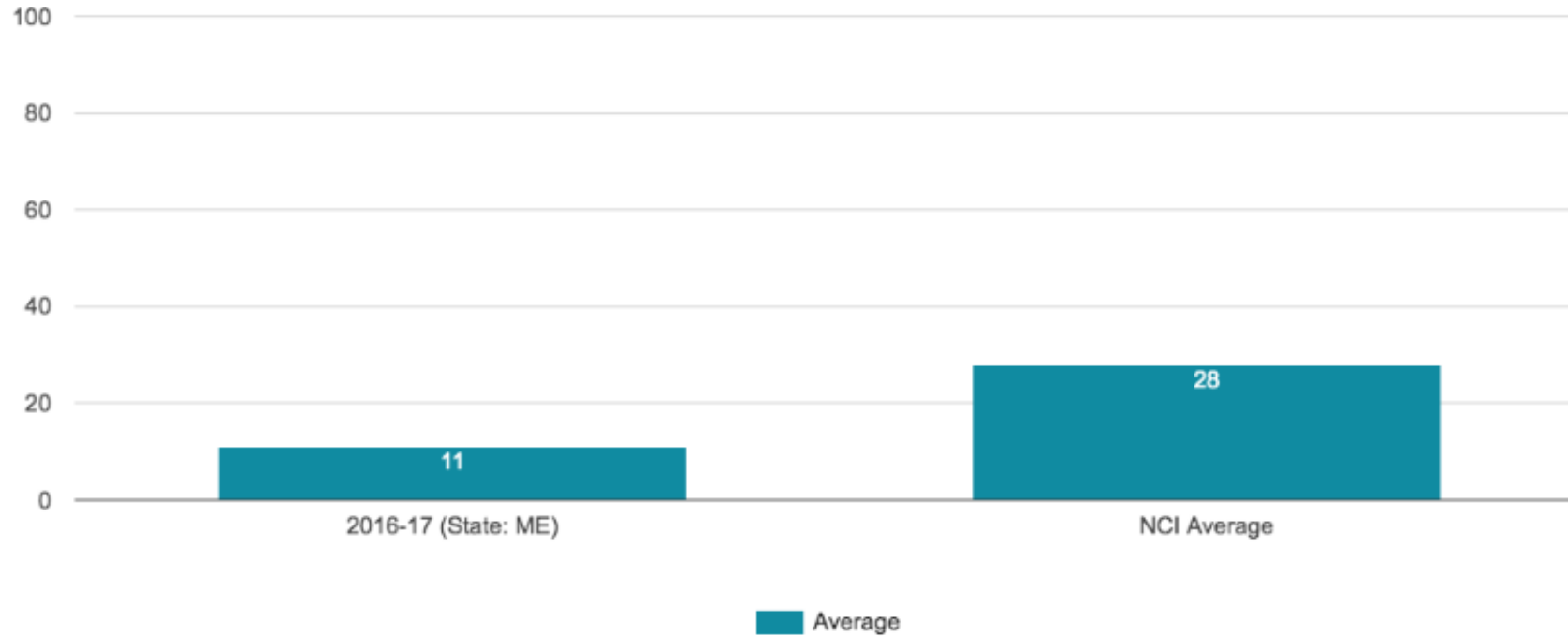
Paid individual community job

Proportion of people who has a job in the community: Individual jobs

State N = 78 | NCI N = 3353



Key Survey Results



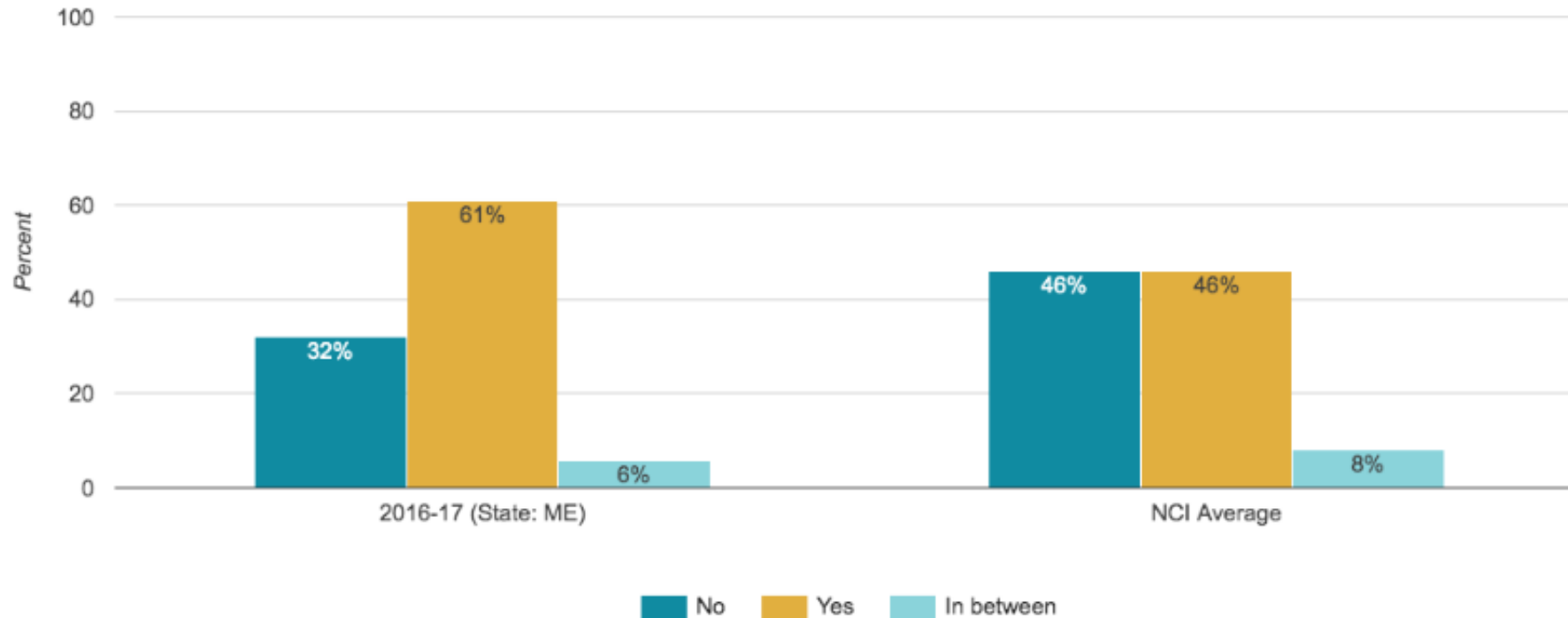
Hours- Individual Job With Publicly Funded Supports

Average number of bi-weekly hours, individual jobs with publicly funded supports

State N = 37 | NCI N = 1157



Key Survey Results



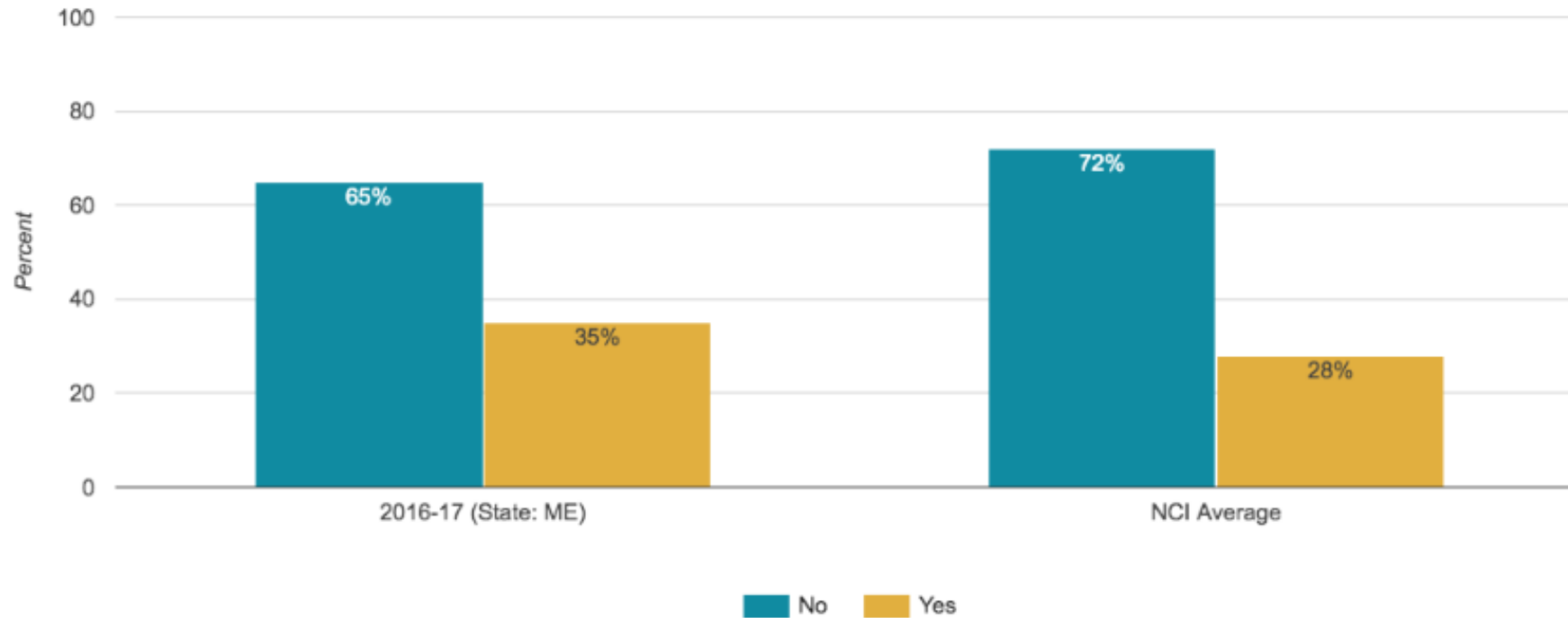
Would Like a Paid Job in the Community

Proportion of people who were reported not to have a job in the community and who reported they would like a job in the community

State N = 192 | NCI N = 8311



Key Survey Results



Has Community Employment as a Goal in Service Plan

Proportion of people who has community employment as a goal in their service plan

State N = 386 | NCI N = 19673





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