Department of Health and Human Services

Maine People Living Safe, Healthy and Productive Lives

Paul R. LePage, Governor Mary C. Mayhew, Commissioner

Review of Maine's Adult ID and Autism Services

Based on Data Provided by National Core Indicator's Adult Consumer Survey 2013-14 Report

Office of Aging and Disability Services
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Table of Contents

Overview 2
Access 4
Choice and Decision Making 6
Community Inclusion 8
Health 10
Medications 12
Relationships 13
Respect and Rights 15
Safety 17
Satisfaction 18
Self Determination 19
Service Coordination 20
Wellness 21
Work 22
Demographics 26

Overview

Taken from 2013-14 NCI Adult Consumer Survey Report:
The National Core Indicators (NCI) are standard measures used across states to assess the outcomes of services provided to individuals with intellectual/developmental disabilities and their families. Indicators address key areas such as employment, respect/rights, service planning, community inclusion, choice, and health and safety. The data that result from NCI surveys are often used to inform strategic planning, produce legislative reports, and prioritize quality improvement initiatives. Many states also share the data with stakeholder groups such as Quality Councils and use the stakeholder feedback to help set priorities and establish policy direction.

The NCI Adult Consumer Survey is administered to individuals with a developmental disability who receive at least one service other than case management.

The data presented in this report is pulled from the larger 2013-14 NCI Adult Consumer Survey report. This report focuses specifically on the results from Maine and compares those results to the NCI National Average which is comprised of 28 states, the District of Columbia, and one regional council. NCI provided data on 13 domains as well as Demographic data. Each of these domains is provided their own section which can be found in the Table of Contents.

In Maine, 400 interviews were completed from a random sample of adults over age 18 who receive at least one service in addition to case management. According to NCI, "A sample size of 400 guarantees valid comparisons to be made across states with a 95% confidence level and a margin of error of +/- 5%, no matter how large the service population size. A 95% confidence level and a margin of error of +/-5% is mandatory for each state's sample to be included in this report."

Each section begins with a quote from the NCI report regarding that specific domain. Following that is a quick summary of the data regarding Maine's comparison to the NCI National Average. When appropriate, a graph may accompany a section in order to provide a visual representation of the data gathered.

Accompanying each section is a table that details the data provided. The images on page 3 explain how to read the tables.

Areas Maine is Doing Well	Areas of Concern
Choice and Decision Making	Access (Transportation)
Community Inclusion	Health
Relationships	Respect and Rights
Work	Safety
	Satisfaction
	Service Coordination

Title of Table (Health Is the NCI Domain in this example)

Maine's Average (percent of Maine Respondents who experience indicator to the left)

NCI National Average (average percent of all NCI respondents who experience indicator to the left)

Maine's standing when compared to NCI National Average

NCI Indicator Indicators are arranged based on Maine's Standing (in this example Maine is above average with respondents having a primary care doctor)

Maine's Health Standings and Indicators	Maine's Average	NCI Average
Above Average		
Had a complete physical exam in the past year (within the last year or less responses)	93%	88%
Had a flu vaccine in the past year (within the last year or less responses)	83%	78%
Have a primary care doctor	99%	98%
Average		
Had a colorectal cancer screening in the past year (among people age 50 and over; within the last year or less responses)	19%	19%
In poor health ('poor health' response only)	5%	5%
Below Average		
Had a dental exam in the past year (within the last year or less responses)	76%	79%
Had a hearing test in the past five years (within five years or less responses)	44%	65%
Had a mammogram test in the past two years (among women age 40 and over; within the past two years or less responses)	62%	75%
Had a Pap test in the past three years (among women; within the past three years or less responses)	52%	67%
Had a pneumonia vaccine	34%	43%
Had an eye exam in the past year (within the last year or less responses)	44%	59%

Some domains have indicators that contain multiple responses. In those situations, the data is presented similar to the image above with some minor changes. The changes can be viewed in the image below.

Indicator that contains multiple responses

Responses to the indicator listed above

Maine's Access Standings and Indicators	Maine's Average	NCI Average
Below Average		
Always have a way to get places when they want to go somewhere ('yes' responses only)	67%	84%
Get the services they need ('yes' responses only)	37%	82%
Staff have adequate training to meet person's needs ('yes' responses only)	80%	93%
Use various types of transportation (not mutually exclusive)		
Above Average		
Ride from family or friends	53%	48%
Ride from staff in provider van or vehicle	58%	52%
Ride from staff in staff's car	60%	39%
Specialized transportation such as paratransit service	35%	13%
Taxi service	10%	3%
Transports self	45%	18%
Average		
Public transportation such as bus	13%	13%

Access

NCI on Access:
Publicly funded services are readily available to individuals who need and qualify for them.

There are three Access indicators. Modes of transportation used are also identified.

Of the 3 indicators Maine was below average on all 3 when compared to the NCI average. This data and related information can be found in the table on page 3.

Maine ranked the lowest amongst all participating states regarding getting the services they need, and regarding staff having adequate training.

The most common mode of transportation for Maine are rides from staff in staff's car, compared to the NCI average in which the most common mode are rides from staff in provider van or vehicle.

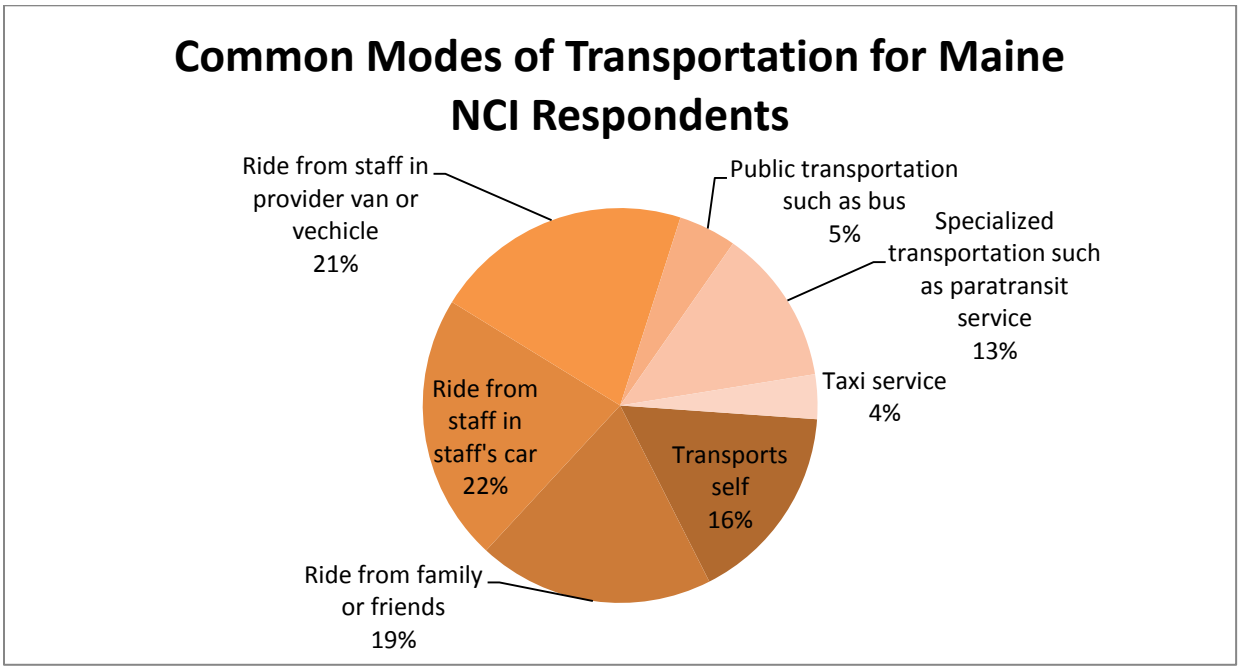

Figure 1

Maine's Access Standings and Indicators	Maine's Average	NCI Average
Below Average		
Always have a way to get places when they want to go somewhere ('yes' responses only)	67%	84%
Get the services they need ('yes' responses only)	37%	82%
Staff have adequate training to meet person's needs ('yes' responses only)	80%	93%
Use various types of transportation (not mutually exclusive)		
Above Average		
Ride from family or friends	53%	48%
Ride from staff in provider van or vehicle	58%	52%
Ride from staff in staff's car	60%	39%
Specialized transportation such as paratransit service	35%	13%
Taxi service	10%	3%
Transports self	45%	18%
Average		
Public transportation such as bus	13%	13%

Choice and Decision Making

NCI on Choice and Decision Making:
The Choice and Decision-Making indicator is:
The proportion of people who make choices about their everyday lives, including: housing, roommates, daily routines, jobs, support staff or providers, social activities, and what to spend money on.
The Adult Consumer Survey includes nine choice items that correspond to the Choice indicator; all but one item, "Chose Case Manager" were risk-adjusted.

Two Choice composite scale scores were produced by adding and averaging Choice items. The Life Decisions scale refers to choice of: residence, work, day activity, staff, and roommates. The Everyday Choices scale refers to choice of: daily schedule, how to spend money, and free time activities. Both scales were risk-adjusted.

Of the 11 Core Indicators regarding Choice and Decision Making, Maine was below average for 4 indicators, average for 3 indicators, and above average for 4 indicators when compared to the NCI average. The data and related information can be found in the table on page 5.

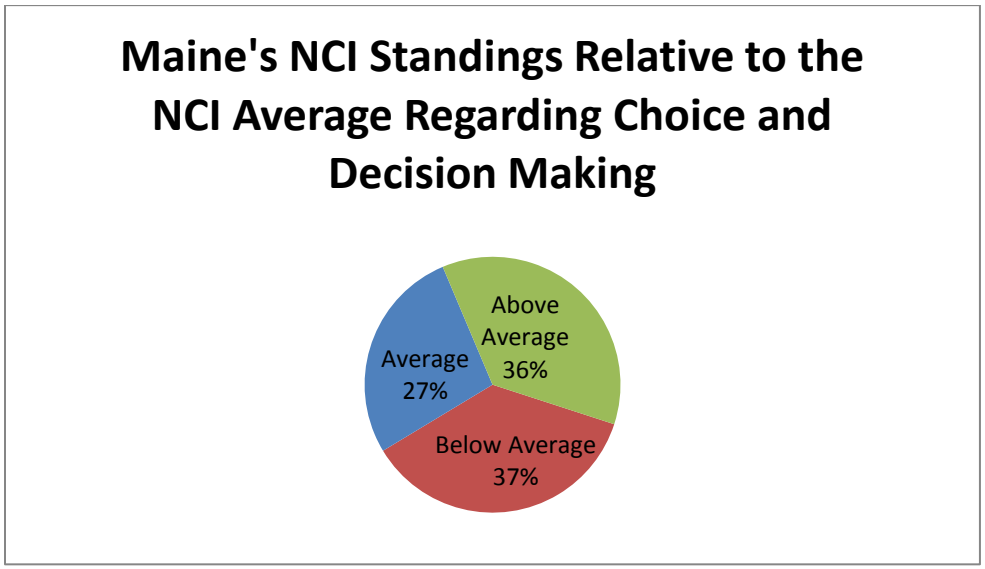

Figure 2

Maine's Choice and Decision Making Standings and Indicators	Maine's Average	NCI Average
Above Average		
Choose or help decide how to spend free time	90%	89%
Choose or help decide their daily schedule	83%	81%
Chose or had some input in choosing where they live if not living at home with family	51%	49%
Chose or had some input in choosing where they work (among those determined to have a paid community job from the Background Section)	88%	81%
Average		
Chose or had some input in choosing where they go during the day (among those with a day program or activity)	58%	58%
Chose or were aware they could request to change their case manager/service coordinator	63%	63%
Everyday Choices Scale	86%	86%
Below Average		
Choose or help decide what to buy with their money	85%	86%
Chose or had some input in choosing their roommates if not in the family home	40%	43%
Chose or were aware they could request to change the staff who help them at their home, job, or day program or activity	58%	64%
Life Decisions Scale	55%	57%

Community Inclusion

NCI on Community Inclusion:
People have support to participate in everyday community activities.

There is one Community Inclusion indicator:
The proportion of people who regularly participate in integrated activities in their communities.

Seven items from the Adult Consumer Survey were used to measure this indicator. The seven items were risk-adjusted.

Results from the Community Inclusion composite scale score were produced by adding four of the items: the number of times the person went shopping, on errands, out for entertainment, and out to eat. The Community Inclusion scale was risk-adjusted.

Of the 1 indicator and the 7 measured items, Maine was below average on 1 item and above average on 7 items when compared to the NCI average. This data and related information can be found in the table on page 7.

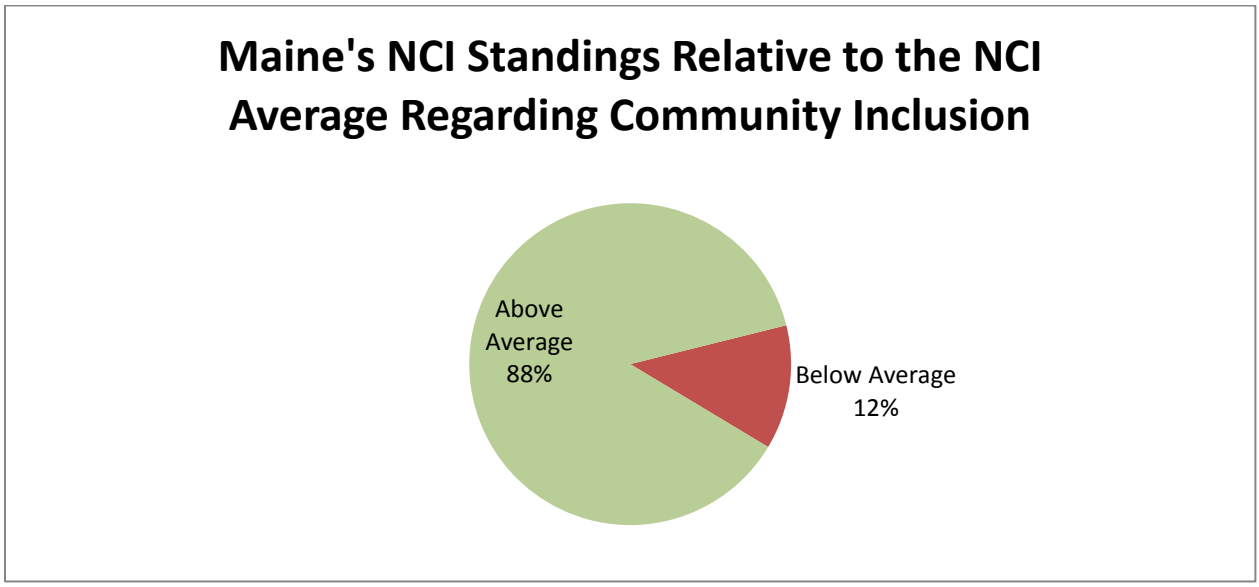

Figure 3

Maine's Community Inclusion Standings and Indicators	Maine's Average	NCI Average
Above Average		
Community Inclusion Scale Score	19.2	13.3
Number of times people reported they went on vacation in the past year	1	0.8
Number of times people reported they went out for exercise in the past month	7.8	6.6
Number of times people reported they went out on errands in the past month	5	2.8
Number of times people reported they went out shopping in the past month	5.8	4.1
Reported number of times people went out in the past month for entertainment	3.2	2.7
Reported number of times people went out to eat in the past month	4.9	3.6
Below Average		
Number of times people reported they went out to religious services in the past month	1.1	1.8

Health

NCI on Health:
People secure needed health services.

The Health indicators are collected with the Background Information section of the Adult Consumer Survey. There are 12 core health indicators.

Of the 12 Indicators NCI lists, only 11 were expanded upon. (Data appears to be missing on Men 50 and over who has a PSA (prostate exam) in the past year).

Of the 11 expanded upon indicators, Maine was below average on 5, average on 2, and above average on 3 when compared to the NCI average. The data and related information can be found in the table on page 9.

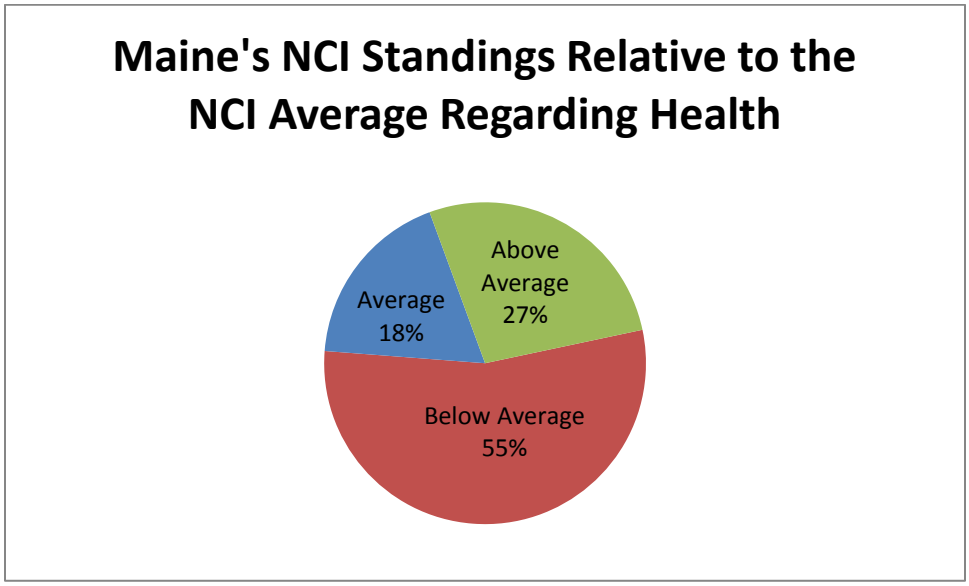

Figure 4

Maine's Health Standings and Indicators	Maine's Average	NCI Average
Above Average		
Had a complete physical exam in the past year (within the last year or less responses)	93%	88%
Had a flu vaccine in the past year (within the last year or less responses)	83%	78%
Have a primary care doctor	99%	98%
Average		
Had a colorectal cancer screening in the past year (among people age 50 and over; within the last year or less responses)	19%	19%
In poor health ('poor health' response only)	5%	5%
Below Average		
Had a dental exam in the past year (within the last year or less responses)	76%	79%
Had a hearing test in the past five years (within five years or less responses)	44%	65%
Had a mammogram test in the past two years (among women age 40 and over; within the past two years or less responses)	62%	75%
Had a Pap test in the past three years (among women; within the past three years or less responses)	52%	67%
Had a pneumonia vaccine	34%	43%
Had an eye exam in the past year (within the last year or less responses)	44%	59%

Medications

NCI on Medications:
Medications are managed effectively and appropriately.

There is one Medications indicator collected using the Background Information section of the Adult Consumer Survey.

Maine is above average on this indicator when compared to the NCI average.

Maine's Medications Standing and Indicator	Maine's Average	NCI Average
Above Average		
Take medication for at least one of the following: mood disorders, anxiety, behavior problems, and/or psychotic disorder	60%	55%

Relationships

NCI on Relationships:
People have friends and relationships.

There are six Relationship indicators.

Of the 6 indicators, one is broken down into two separate measurable items: Able to see (a) families and (b) friends whenever they want. Of these 7 items, Maine is below average for 3 items, average for 1 item, and above average for 3. The data and related information can be found in the table on page 12.

Maine ranked highest amongst all participating states regarding going on dates with out or with some restrictions.

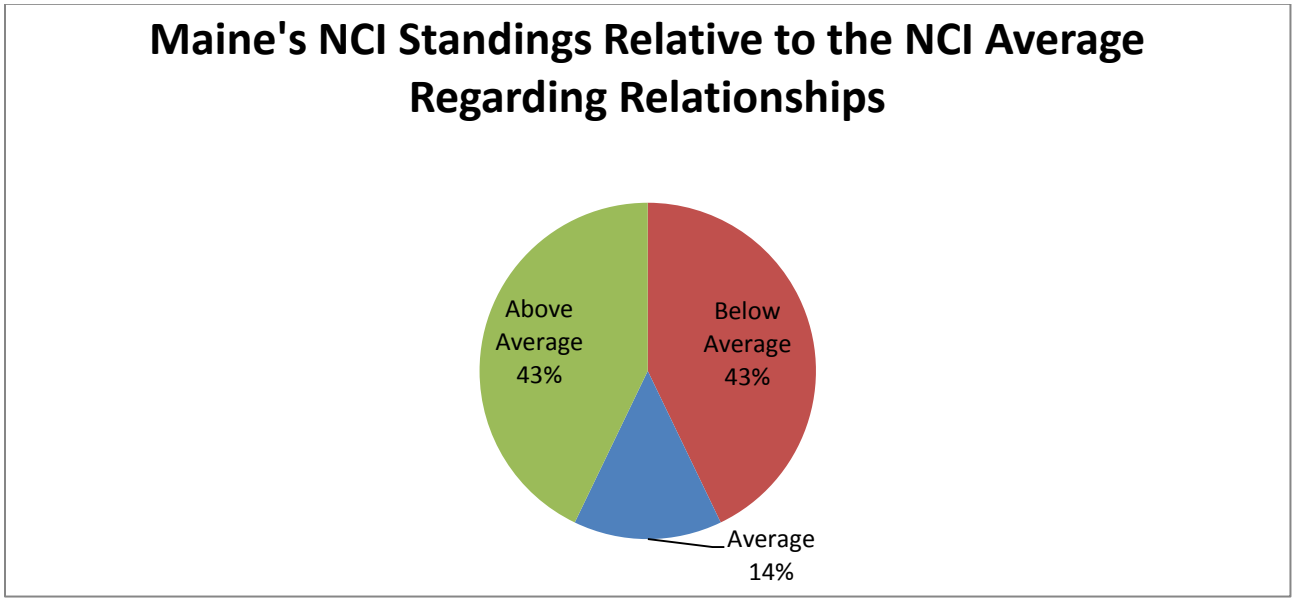

Figure 5

Maine's Relationships Standings and Indicators	Maine's Average	NCI Average
Above Average		
Can go on a date if they want or can date with some restriction ('yes, can date' and 'yes, can date with some restriction or rules' responses)	95%	83%
Feel lonely at least half the time ('yes' and 'sometimes' responses)	48%	40%
Have friends who are not staff or family members ('yes' responses only)	82%	76%
Average		
Can help other people if they want, at least some of the time ('yes' responses only)	86%	86%
Below Average		
Have a best friend (may be staff or family)	76%	79%
Have family they see and the support needed to see their family when they want ('yes' responses only)	73%	80%
Have friends (may be staff or family) and the support needed to see their friends when they want ('yes' responses only)	66%	78%

Respect and Rights

NCI on Respect and Rights:
People receive the same respect and protections as others in the community.

There are four Respect and Rights indicators:
1. The proportion of people whose basic rights are not respected by others, including:
   a. People enter the home without permission
   b. People enter bedroom without permission
   c. Restrictions on being alone with others
   d. Mail gets opened without permission
   e. Restrictions on using the phone or Internet
2. The proportion of people who report satisfaction with the amount of privacy they have.
3. The proportion of people indicating that most support staff treats them with respect.
4. The proportion of people who have participated in a self-advocacy group meeting, conference, or event.

Of the 8 measured items, Maine was below average on 7 items and above average on 1 item when compared to the NCI average. This data and related information can be found in the table on page 14.

Maine ranked lowest among all participating states regarding staff being nice and polite and regarding people knocking before entering their home.

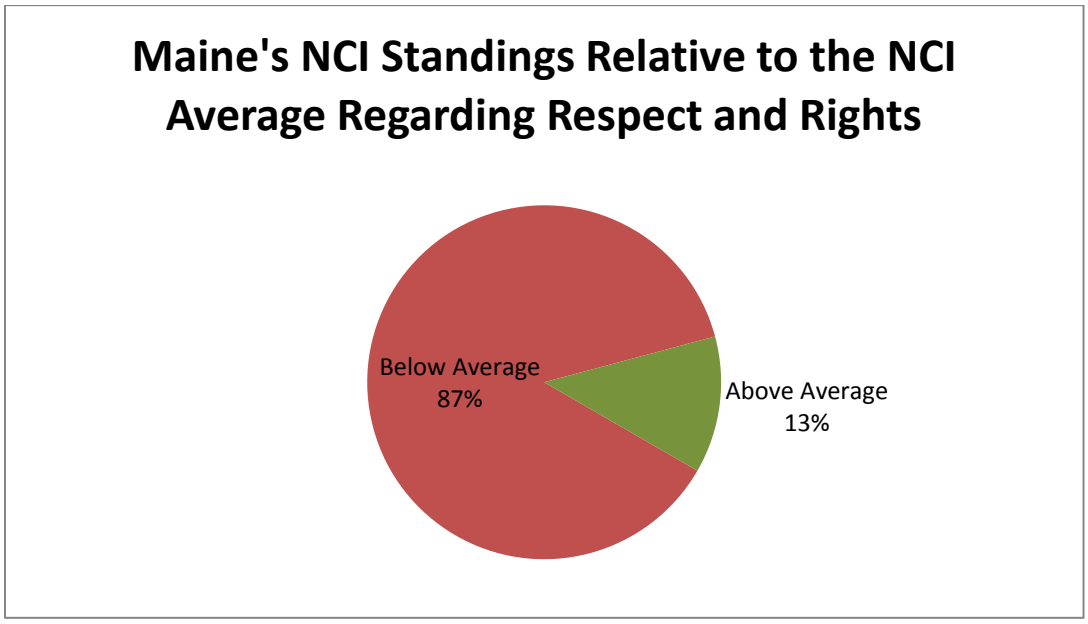

Figure 6

Maine's Respect and Rights Standings and Indicators	Maine's Average	NCI Average
Respect and Rights		
Above Average		
Others never read their mail without permission ('no' responses only)	91%	86%
Below Average		
Can be alone at home with visitors ('yes' responses only)	75%	77%
Can use phone and Internet without restriction ('yes, without restriction' response only)	85%	89%
Have attended a self-advocacy event or chose not to ('yes' and 'no, chose not to' responses)	30%	33%
Have enough privacy at home ('yes' responses only)	84%	91%
People always knock before entering bedroom ('yes' responses only)	74%	83%
People always knock before entering home ('yes' responses only)	74%	89%
Staff (at home, work, and/or day activity or program) are nice and polite ('yes' responses only)	77%	93%

Safety

NCI on Safety:
People are safe from abuse, neglect, and injury.
There are two Safety indicators:
1. The proportion of people who report that they never feel scared or afraid in their home, neighborhood, workplace, and day program/daily activity.
2. The proportion of people who report having someone to go to for help when they feel afraid.

Of the 4 measurable items, Maine is below average on all of them when compared to the NCI average.

Maine ranked lowest among participating states regarding rarely or never feeling scared to leave their home, neighborhood, and day program/work.

Maine's Safety Standings and Indicators	Maine's Average	NCI Average
Below Average		
Have someone to go to for help if they ever feel scared ('yes' responses only)	92%	93%
Rarely or never feel scared or afraid at their work or day program ('no' responses)	72%	86%
Rarely or never feel scared or afraid in their home ('no' responses)	67%	82%
Rarely or never feel scared or afraid in their neighborhood ('no' responses)	71%	83%

Satisfaction

NCI on Satisfaction:
People are satisfied with the services and supports they receive.

There are seven Satisfaction indicators.

Of the 7 indicators, Maine is below average for 4 of them and above average for 3 of them when compared to the NCI average. This data and resulting information can be found in the table below.

Maine ranked lowest among all participating states regarding liking their home and liking where they go or what they do at day program.

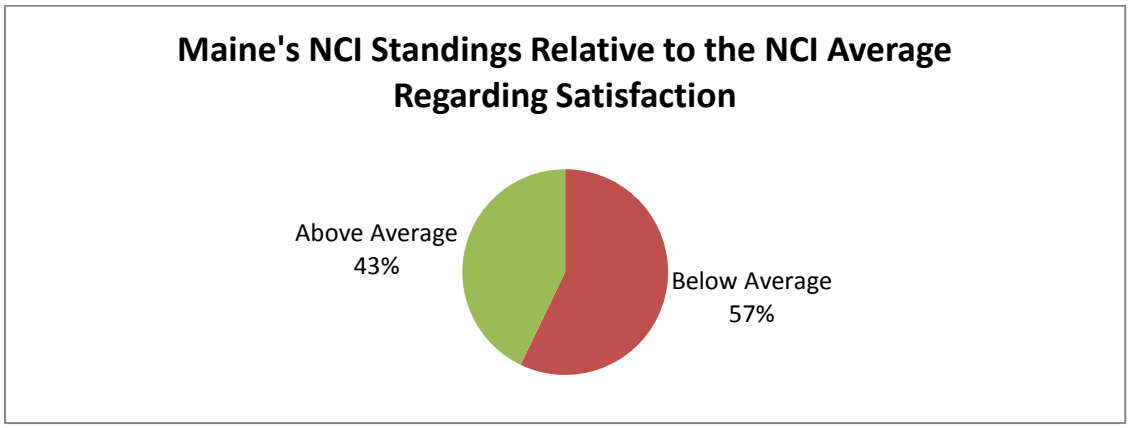

Figure 7

Maine's Satisfaction Standings and Indicators	Maine's Average	NCI Average
Above Average		
Attend a day program or activity and want to go someplace else or do something different during the day ('yes' responses only)	39%	34%
Have a paid job in the community and want to work somewhere else* ('yes' responses only)	40%	30%
Would like to live somewhere else ('yes' responses only)	32%	26%
Below Average		
Attend a day program or activity and likes where they go or what they do ('yes' responses only)	76%	88%
Have a paid job in the community and like where they work ('yes' responses only)	90%	93%
Like their home ('yes' responses only)	79%	90%
Talk with their neighbors at least some of the time ('yes, but not often' and 'yes, often' responses)	55%	65%

Self Determination

NCI on Self Determination:
People have authority and are supported to direct and manage their own services.

There are six indicators measured by the Adult Consumer Survey.

Only one indicator was applicable for Maine. All other indicators are dependent upon answers "among those self-directing", and since there were less than 20 self-directing respondents the other remaining 6 indicators were not applicable.

Maine's Self Determination Standings and Indicators	Maine's Average	NCI Average
Below Average		
Using a self-directed supports option	4%	8%
Not Applicable		
Can make changes to their individual budget/services if they need to (among those self-directing; 'yes' responses only)	N/A	82%
Have help deciding how to use their individual budget/services (among those self-directing; 'yes' responses only)	N/A	89%
Need more help deciding how to use their budget/services (among those self-directing; 'yes' and 'maybe' responses)	N/A	29%
Receive enough information about their budget/services (among those self-directing; 'yes' responses only)	N/A	77%
Reported that someone walked with them about their individual budget/ services (among those self-directing; 'yes' responses only)	N/A	78%

Service Coordination

NCI on Service Coordination:
Service coordinators are accessible, responsive, and support the person's participation in service planning.

There are seven Service Coordination indicators.

Of the 7 indicators, Maine was below average for 6 indicators and above average for 1 when compared to the NCI average. This data and related information can be found in the table below.

Maine ranked lowest among all participating states regarding support workers coming when they're supposed to.

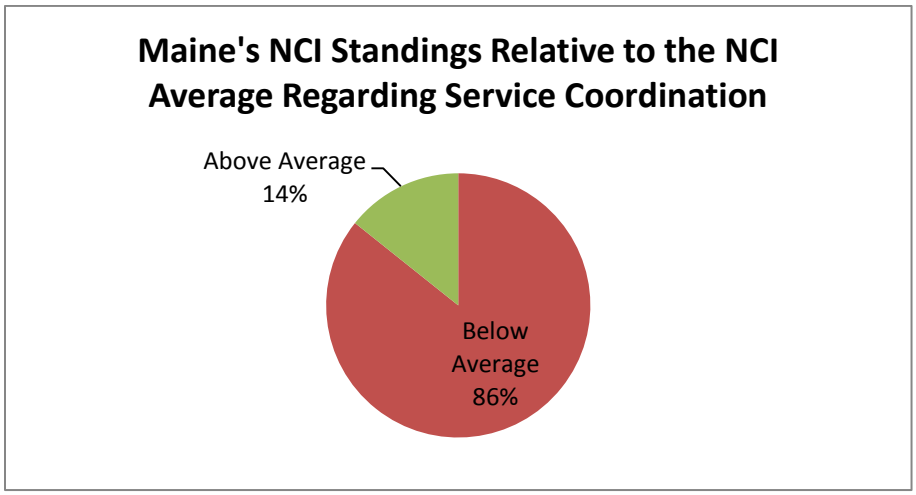

Figure 8

Maine's Service Coordination Standings and Indicators	Maine's Average	NCI Average
Above Average		
Helped make their service plan ('yes' responses only)	88%	87%
Below Average		
Get the help they need to work out problems they have with their support workers ('yes' responses only)	88%	92%
Met their service coordinator/case manager ('yes' responses only)	94%	95%
Service coordinator/case manager asks them what they want ('yes' responses only)	79%	88%
Service coordinator/case manager calls them back right away ('calls back right away' responses only)	55%	75%
Service coordinator/case manager helps them get what they need ('yes' responses only)	83%	88%
Support workers come when they are supposed to ('yes' responses only)	83%	94%

Wellness

NCI on Wellness:
There is one Wellness indicator collected with the Background Information section of the Adult Consumer Survey:
1. The proportion of people who maintain healthy habits in such areas as:
a. Exercise
b. Weight
c. Smoking

Maine was above the NCI average for engaging in regular physical activity, chewing or smoking tobacco, and being obese and overweight.

Maine's Wellness Standings and Indicators	Maine's Average	NCI Average
Above Average		
Chew or smoke tobacco	8%	7%
Engage in regular physical activity (at least 30 minutes three times a week)	27%	22%
BMI category		
Above Average		
Obese	34%	33%
Overweight	32%	29%
Below Average		
Normal Weight	30%	33%
Underweight	4%	5%

Work

NCI on Work:
People have support to find and maintain community-integrated employment. There are 11 Work indicators measured by the Adult Consumer Survey.

Additionally, NCI reports on the type of paid community jobs individuals have (individually-supported, competitive, or group-supported), as well as the most common jobs individuals hold.

Of the 11 work indicators, Maine was below average for 2 indicators, average for 1 indicator, and above average for 6 indicators when compared to the NCI average. 2 indicators had less than 20 respondents and as a result were not applicable by NCI standards. This data and related information can be found in the table on pages 22-23.

Maine ranked the highest out of all participating states of consumers who want a job in the community.

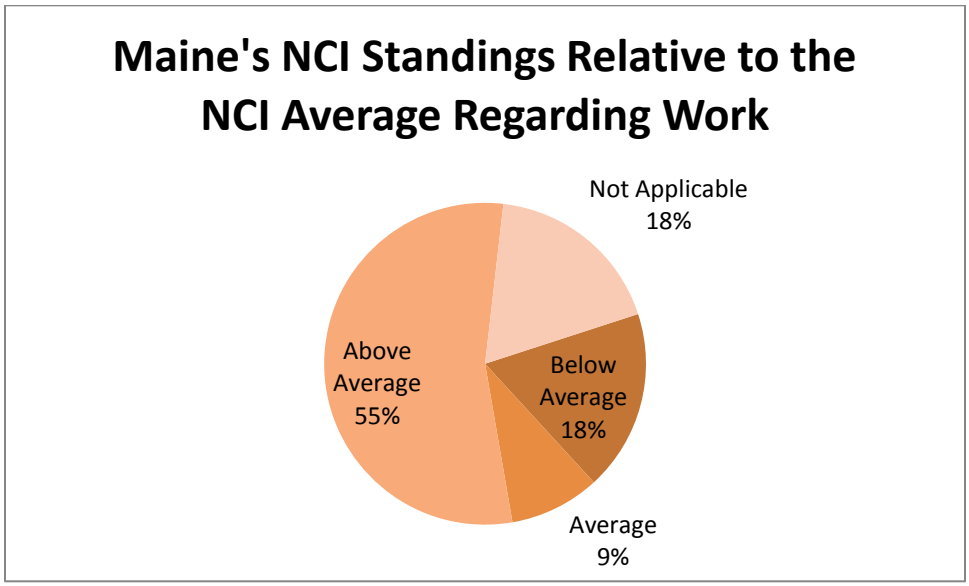

Figure 9

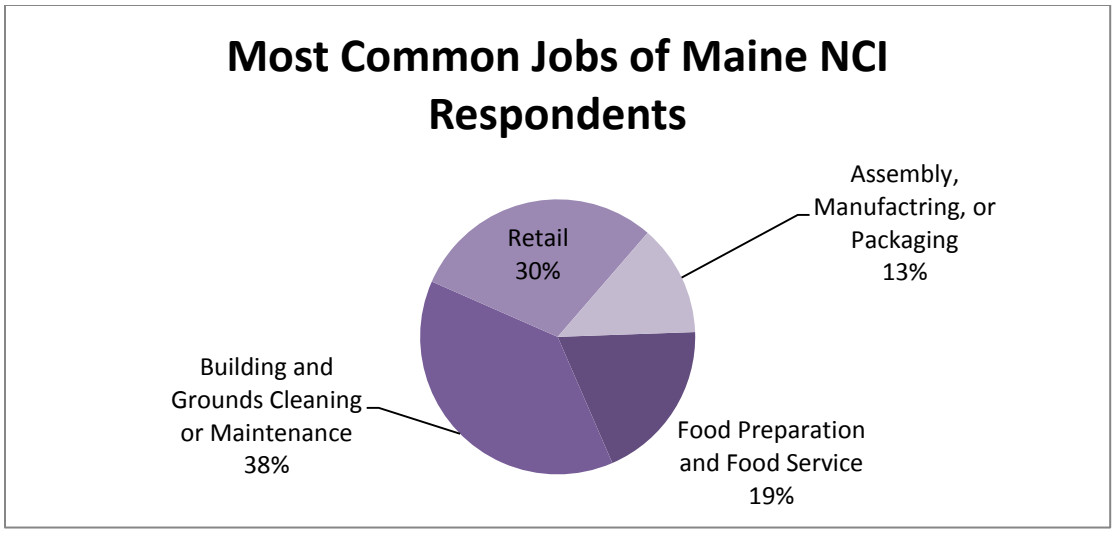

Figure 10

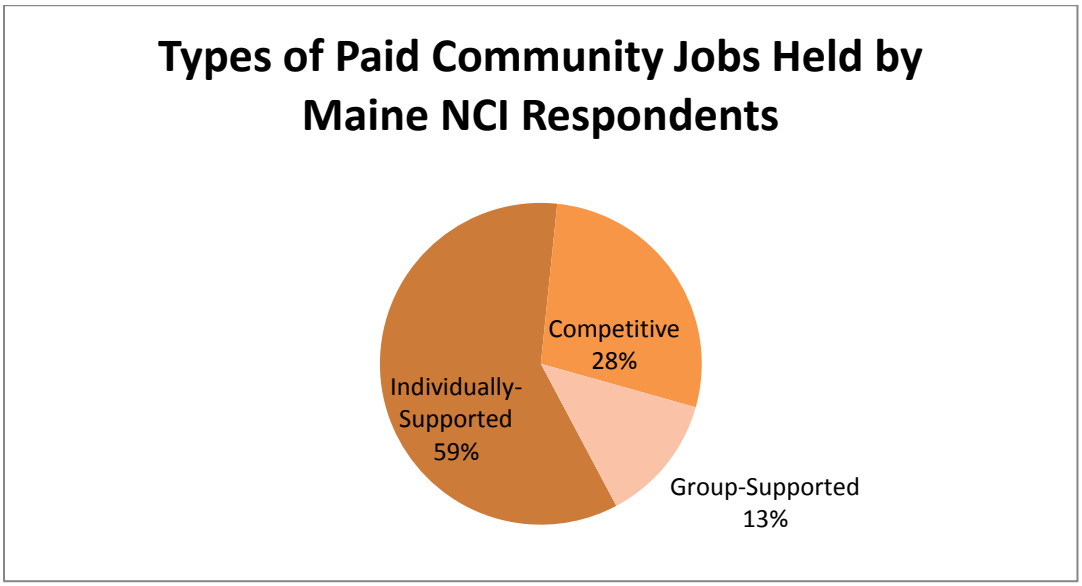

Figure 11

Maine's Work Standings and Indicators	Maine's Average	NCI Average
Above Average		
Attend a day program or regular activity	74%	71%
Do volunteer work	42%	32%
Have a paid job in the community	24%	16%
Have community employment as a goal in their service plan	32%	25%
Worked 10 of the past 12 months in community employment (among those reported to have a job in the community	91%	84%
Would like a job in the community (among those without a job; 'yes' responses)	66%	49%
Average		
Receives paid vacation and/or sick time at their job (among those reported to have a job in the community)	25%	25%
Below Average		
Length of employment in current job (among those reported to have a job in the community) *Measured in Average Months Employed*	63	69.4
Average number of biweekly hours by type of community employment		
Below Average		
Individually-Supported	16	24
N/A (less than 20 respondents)		
Competitive	N/A	28
Group-Supported	N/A	32
Four most common job types (among those reported to have a job in the community)		
Above Average		
Assembly, Manufacturing, or Packaging	11%	9%
Retail	25%	15%
Below Average		
Building and Grounds Cleaning or Maintenance	32%	33%
Food Preparation and Food Service	16%	18%

Type of employment among those reported to have a paid job in the community		
Above Average		
Individually-Supported	60%	33%
Below Average		
Competitive	28%	34%
Group-Supported	13%	34%

Demographics

In the table on page 24-29 is demographic information that was collected by NCI during their survey.

Based on this information, the typical Maine consumer is a 46 year old, non-Hispanic, English speaking white male. The typical consumer has a mild level of Intellectual Disability, may have an anxiety disorder and/or neurological problem, and is able to move and communicate without aids. The typical consumer is in fairly good health, lives in a 1-3 person Group Home, and does not require additional support for destructive, disruptive, or self-injurious behavior.

Demographic and Maine's Standing	Maine's Average	NCI Average
Age		
Above Average	46	43
Ethnicity		
Don't Know		
Average	1%	1%
Hispanic		
Below Average	2%	4%
Non-Hispanic		
Above Average	98%	95%
Gender		
Female		
Above Average	48%	42%
Male		
Below Average	52%	58%
Level of ID		
Mild		
Above Average	42%	34%
Moderate		
Below Average	27%	29%
No ID		
Below Average	1%	5%

Profound		
Below Average	8%	11%
Severe		
Below Average	11%	13%
Unknown		
Above Average	6%	5%
Unspecified		
Above Average	5%	3%
Mobility		
Don't Know		
Average	0%	0%
Moves With Aids or Uses Wheelchair Independently		
Above Average	16%	15%
Moves Without Aids		
Above Average	78%	76%
Non-Ambulatory		
Below Average	6%	9%
Mood, Anxiety, Behavior, Psychotic, and Other Mental Illness		
Anxiety Disorder		
Above Average	39%	25%
Behavior Challenges		
Above Average	38%	31%
Mood Disorder		
Above Average	36%	33%
Other Mental Illness or Psychiatric Diagnosis		
Above Average	17%	12%
Psychotic Disorder		
Below Average	10%	14%

Other Disabilities		
Alzheimer's Disease or Other Dementia		
Average	4%	4%
Autism Specturm Disorder		
Average	17%	17%
Brain Injury		
Above Average	7%	5%
Cerebral Palsy		
Below Average	11%	17%
Chemical Dependency		
Average	1%	1%
Down Syndrome		
Average	11%	11%
No Other		
Above Average	14%	13%
Other		
Below Average	21%	23%
Prader-Willi Syndrome		
Below Average	0%	1%
Seizure Disorder or Neurological Problem		
Below Average	25%	31%
Vision and/or Hearing Impairment		
Below Average	15%	17%
Overall Health		
Don't Know		
Average	1%	1%
Excellent		
Below Average	11%	12%

Fairly Good		
Above Average	43%	39%
Poor		
Above Average	5%	4%
Very Good		
Below Average	41%	44%
Primary Language		
English		
Above Average	99%	98%
Other		
Below Average	1%	2%
Primary Means of Expression		
Communication Device		
Average	1%	1%
Don't Know		
Average	0%	0%
Gestures		
Below Average	14%	19%
Other		
Below Average	0%	2%
Sign Language		
Above Average	3%	2%
Spoken		
Above Average	82%	76%
Race		
American Indian/ Alaska Native		
Average	1%	1%
Asian		

Below Average	0%	3%
Black or African-American		
Below Average	1%	21%
Don't Know		
Average	1%	1%
Other Race Not Listed		
Below Average	0%	2%
Pacific Islander		
Below Average	0%	1%
Two or More Races		
Average	1%	1%
White		
Above Average	96%	71%
Residence		
Don’t Know		
Average	0%	0%
Foster Care or Host Home		
Above Average	14%	8%
Group Home 1-3 People w/ Disabilities or Agency Operated Apartment		
Above Average	28%	13%
Group Home 4-6 People w/ Disabilities		
Above Average	16%	15%
Group Home 7-15 People w/ Disabilities		
Below Average	1%	5%
Independent Home or Apartment, or Shared w/ Roommate		
Below Average	16%	17%
Other		
Above Average	6%	3%

Parent or Relative's Home		
Below Average	19%	35%
Private Specialized Institutional Facility For People w/ ID/DD (16 or More Residents)		
Below Average	0%	1%
Public Specialized Institutional Facility For People w/ ID/DD (16 or More Residents)		
Below Average	0%	3%
Specialized Institutional Facility For People w/ ID/DD - Public or Private Unknown		
Average	0%	0%
Support to Manage Destructive Behavior		
Don't Know		
Average	2%	2%
Extensive		
Above Average	9%	7%
None		
Below Average	67%	71%
Some		
Above Average	23%	21%
Support to Manage Disruptive Behavior		
Don't Know		
Average	1%	1%
Extensive		
Above Average	13%	10%
None		
Below Average	48%	57%
Some		
Above Average	38%	31%

Support to Manage Self-Injurious Behavior		
Don't Know		
Below Average	1%	2%
Extensive		
Above Average	8%	6%
None		
Below Average	65%	73%
Some		
Above Average	25%	19%