Click a Chapter heading to open that chapter
Executive Summary

In-person Survey Overview

NCI History and Activities
Methodology
Data Analysis

Choice and Decision-Making

Chose or had some input in choosing where they live
Chose or had some input in choosing their housemates
Chose or had some help in choosing where they work
Chose or had some input in choosing day program or workshop
Chose staff or were aware they could request to change staff
Chooses or has help deciding their daily schedule
Has enough choice in daily schedule
Chooses or has help deciding how to spend free time
Has enough choice in how to spend free time
Chooses or has help deciding what to buy or has set limits on what to buy with their spending money
Can change their case manager/service coordinator if wants to (proxy respondents were allowed for this question)

Work

Has a paid community job; individual, group and/or in a business that primarily hires people with disabilities
Type of paid community job
Average biweekly hours by type of paid community job
Average hourly wage at paid community job by type of community employment
Average length of employment in current paid community job
Receives paid time off
Job industries
Does not have paid community job and would like a job in the community
Has community employment as a goal in their service plan
Takes classes, training or does something to get a job or do better at current job
Attends day program or sheltered workshop
Volunteers
Self-Direction
Using a self-directed supports option
People who make decisions or have input in making decisions for how budget for services is used
Hires or manages staff
Can make changes to individual budget/services if needed
Has enough help deciding how to use their individual budget/services
Gets information about how much money is left in budget/services
Information about budget/services is easy to understand
Frequency with which the person gets information about budget/services

Community Inclusion, Participation and Leisure
Number of times went out shopping at least once in the past month
Number of times went out on errands at least once in the past month
Number of times went out for entertainment at least once in the past month
Number of times went out to a restaurant or coffee shop at least once in the past month
Number of times went out to religious service or spiritual practice at least once in the past month
Participates as a member in community group
Went away on vacation in the past year
Able to go out and do the things like to do in the community
Gets to do things likes to do in the community as much as wants
Has enough things likes to do when at home
Gets help to learn new things

Relationships
Has friends who are not staff or family members
Has best friend
Wants help to meet or keep in contact with friends
Has friends and can see their friends when they want
Reasons cannot see friends if sometimes or often unable to
Has other ways of talking, chatting, or communicating with friends when cannot see them
Can see or communicate with their family when they want
Often feels lonely
Can go on a date or is married or living with partner
**Satisfaction**

Likes home or where lives
Reasons does not like home
Wants to live somewhere else
Likes paid community job
Wants to work somewhere else
Attends a day program or workshop and wants to go more, less, or the same amount of time
Person wants to go out shopping more, less or the same amount as last month
Person wants to go out for entertainment more, less or the same amount as last month
Person wants to go out to a restaurant or coffee shop more, less or the same amount as last month
Person wants to go out to a religious service or spiritual practice more, less or the same amount as last month
Person wants to be a part of more community groups
Services and Supports help person live a good life

**Service Coordination**

Has met or spoken with case manager/service coordinator
Case manager/service coordinator asks person what s/he wants
Able to contact case manager/service coordinator when wants
Staff come and leave when they are supposed to
Took part in last service planning meeting, or had the opportunity but chose not to
Understood what was talked about at last service planning meeting
Last service planning meeting included people person wanted to be there
Person was able to choose services they get as part of service plan
Talked about learning new things at last service planning meeting
Remembers what is in the service plan
Service plan includes things that are important to person
Knows who to ask if s/he wants to change something about services

Of those who say they want to learn to perform ADLs more independently, the percentage who have a goal in the service plan to increase independence or improve function skill performance in ADLs
Of those who say they want a paid job in the community (and do not currently have one), the percentage who have community employment as a goal in the service plan
Access
Has a way to get places needs to go
Has a way to get places when wants to do something outside of home
Staff have right training to meet person’s needs
Additional services needed

Health
Has a primary care doctor or primary care practitioner
In poor health
Had a complete physical exam in the past year
Had a dental exam in the past year
Had an eye exam or vision screening in the past year
Had a hearing test in the past five years
Had a Pap test in the past three years
Had a mammogram test in the past two years
Last colorectal cancer screening
Had a flu vaccine in the past year

Medication
Takes at least one medication for mood, anxiety, psychotic disorder and/or behavioral challenge
Takes medication for mood, anxiety, and/or psychotic disorders
Number of medications taken for at least one of the following: mood disorders, anxiety, or psychotic disorders if taking at least one medication for this purpose
Takes medication for behavior challenges
Number of medications taken for behavior challenges if taking at least one for this purpose
Has a behavior plan
Has a behavior plan (among those who take medication for a behavior challenge)

Wellness
Exercises or does physical activity at least once per week for 10 minutes or more at a time
Exercises or does physical activity at least once per week that makes the muscles in arms, legs, back, and/or chest work hard
Body Mass Index (BMI) category
Uses nicotine or tobacco products
Rights and Respect

Others (who do not live in the home) let person know before entering home
Has a key to the home
Wants a key to the home
Can lock bedroom if wants
Others let person know before coming into person’s bedroom
Has a place to be alone in the home
Can be alone with friends or visitors at home
There are rules about having friends or visitors in the home
Can stay at home if others in the house go somewhere
Others read person’s mail or email without asking
Can use phone and internet when wants
Has a cell phone or smartphone
Wants a cell phone or smartphone (if does not have one)
Reasons does not have a cell phone or smartphone
Staff treat person with respect
Has attended a self-advocacy group, meeting, conference or event or had the opportunity and chose not to
Has voted in local, state, or federal election, or had the opportunity and chose not to

Safety

Places feels afraid or scared
Has someone to talk to if ever feels afraid or scared

Appendix A: Rules for Recoding and Collapsing Data

Appendix B: State Sample Frames

Appendix C: Unweighted, Un-collapsed and Unadjusted Data