

Guardianship and People with Intellectual and Developmental Disabilities

WHAT DO NCI DATA TELL US THE OUTCOMES OF
PEOPLE WITH AND WITHOUT GUARDIANS

VALERIE J. BRADLEY
PRESIDENT EMERITA, HSRI
AUCE CONFERENCE, NOVEMBER 12, 2018



Overview

Brief overview of current context in the field

Problems with supported decision-making

What is National Core Indicators?

NCI data on characteristics of individuals with and without guardianship

Summary of data analysis

Current Context in the Field: Emphasis on Choice and Decision-Making



The Affordable Health Care Act included a number of provisions that emphasized self direction including the requirement that all federal agencies develop self-direction guidelines

The CMS Settings Rule (2014) reinforces the importance of Individual choice in waiver-funded services including choice of home, room mates, staff, etc.

In 2016, there were 252 publicly funded self direction programs across the country that totaled approximately 1 million people, including those who are elderly and have developmental/other disabilities

In the health care field, there is an increasing emphasis on “shared decision-making”



Constraints to Choice Making for People with Intellectual and Developmental Disabilities

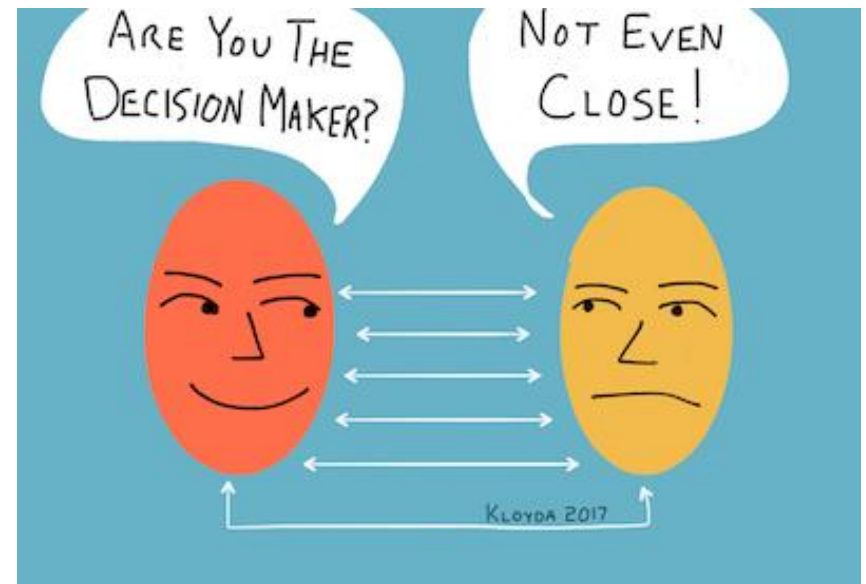
Substituted Decision Making

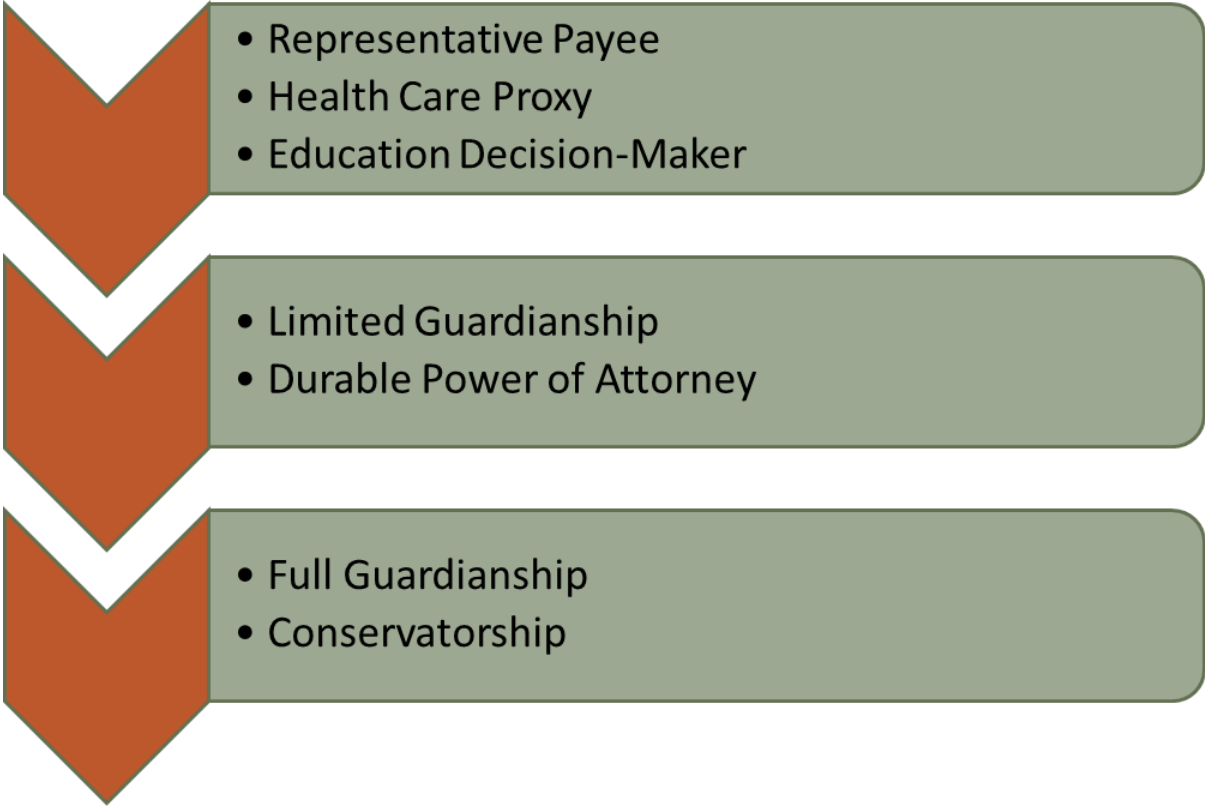
Challenges facing people with ID/DD have led to substituted decision-making through various forms of guardianship. Substituted decision-making has the following impact:

Loss of the ability to make important life decisions without the approval of the guardian

Erosion of the Individual's ability to develop the skills necessary to make decisions

Exclusion from communities because of the inability to enter contracts, make medical decisions, spend money, etc.



- 
- Representative Payee
 - Health Care Proxy
 - Education Decision-Maker

- Limited Guardianship
- Durable Power of Attorney

- Full Guardianship
- Conservatorship

Types of Substituted Decision- Making

Problems with Presumed Incompetence



People may not be included in conversations where important decisions are made about their lives



People don't develop the skills necessary to participate in decisions (e.g., Individual service plan) because they have to rely on others



When they want to make a purchase, get married, open a bank account or enter into a legal agreement, people have to ask permission



Loss of "dignity of risk"



Doctors, dentists and other medical professionals may not provide treatment unless the person has a guardian because of concern the person can not make an informed decision



Guardianship and Outcomes

What do National core indicators Tell Us?

The data represented here are unweighted, NCI averages.
All comparisons are significant at the $p \leq .001$ level

What is NATIONAL CORE INDICATORS (NCI)?

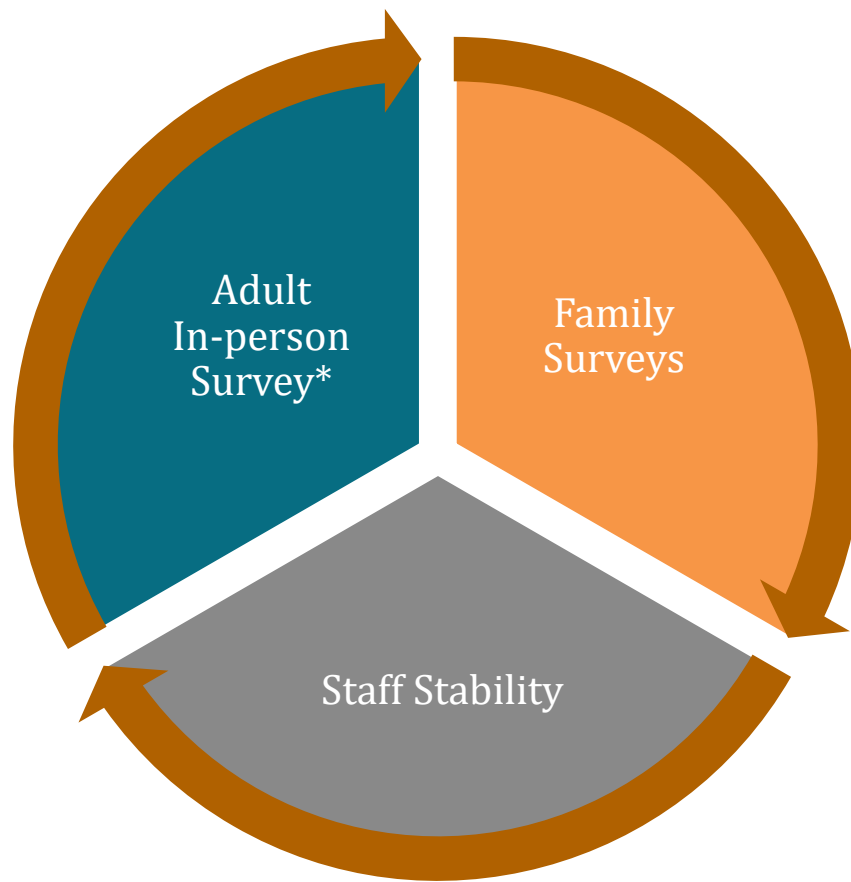


NASDDDS, HSRI & State DD Directors

- ✚ Multi-state collaboration
- ✚ Launched in 1997 in 6 participating states – now in 46 states (including DC) and 22 sub-state areas

Goal: Measure performance of public systems for people with intellectual and developmental disabilities by looking at **outcomes**

- ✚ Help state DD systems assess performance by benchmarking, comparing to other states
- ✚ Domains: employment, community inclusion, choice, rights, health, safety, relationships, service satisfaction etc.



SURVEY TOOLS

*Formerly the Adult Consumer Survey (ACS)

Adult Consumer Survey

Standardized, face-to-face interview with a sample of individuals receiving services

- Background Information - includes health information
- Section I (no proxies allowed)
- Section II (proxies allowed)

No pre-screening procedures

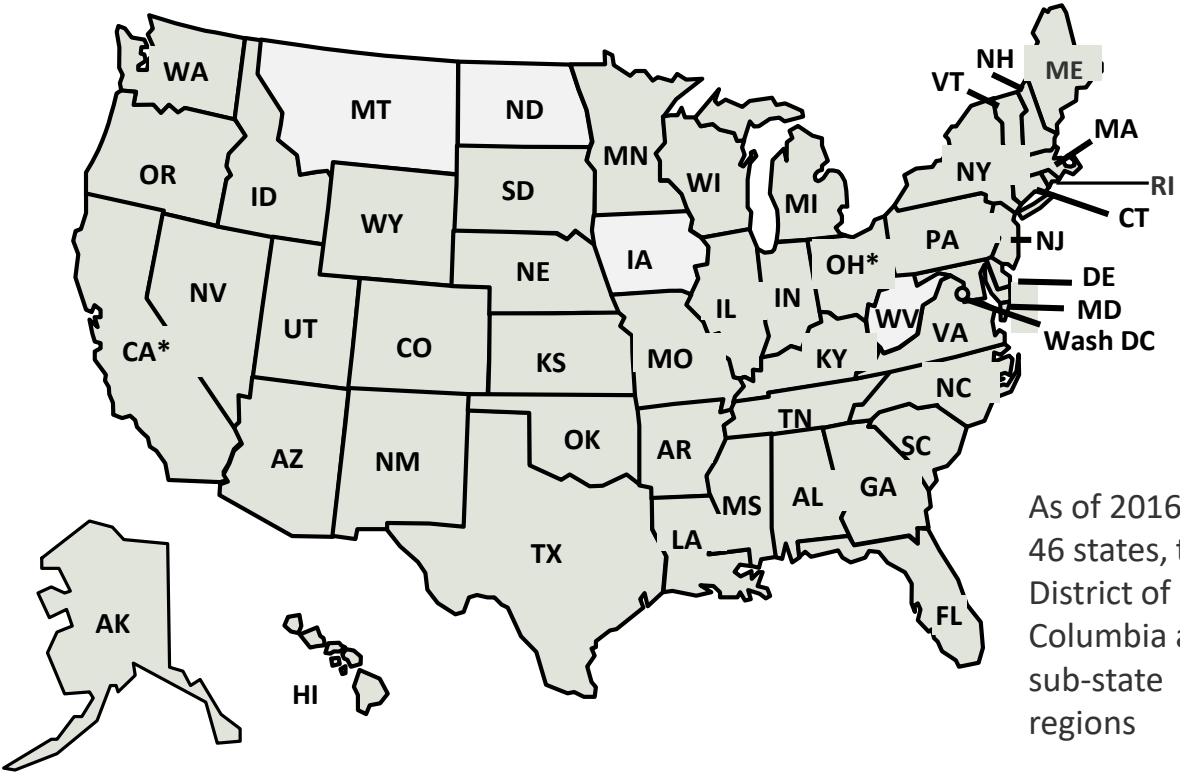
Conducted with adults only (18 and over) receiving at least one service in addition to case management

Section I and Section II together take 50 minutes (on average)

2016-2017 -- Total Sample (N=21,548)



National Core Indicators^(TM) State Participation



As of 2016-17:
46 states, the
District of
Columbia and 22
sub-state
regions



How Does Guardianship Constrain Choice and Outcomes?

NCI data show different outcomes and experiences between adults without guardianship and those with limited and full guardianships.

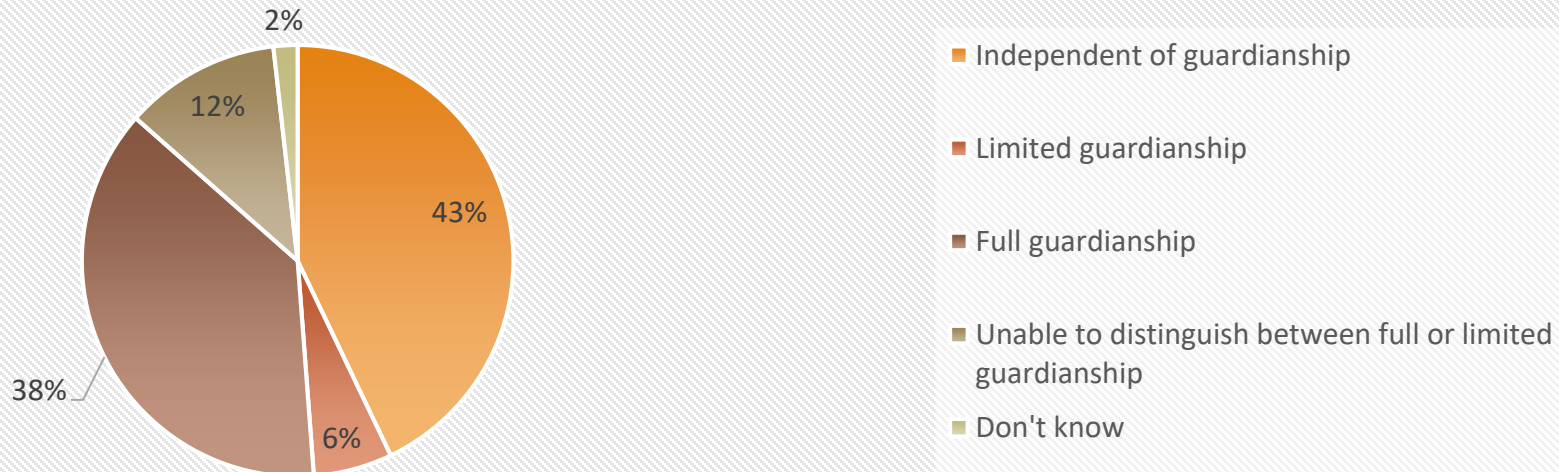
Where the Data Come From

BI-7 Does this person have a legal appointed guardian/conservator (a person who is legally granted authority to make decisions on behalf of the individual)?

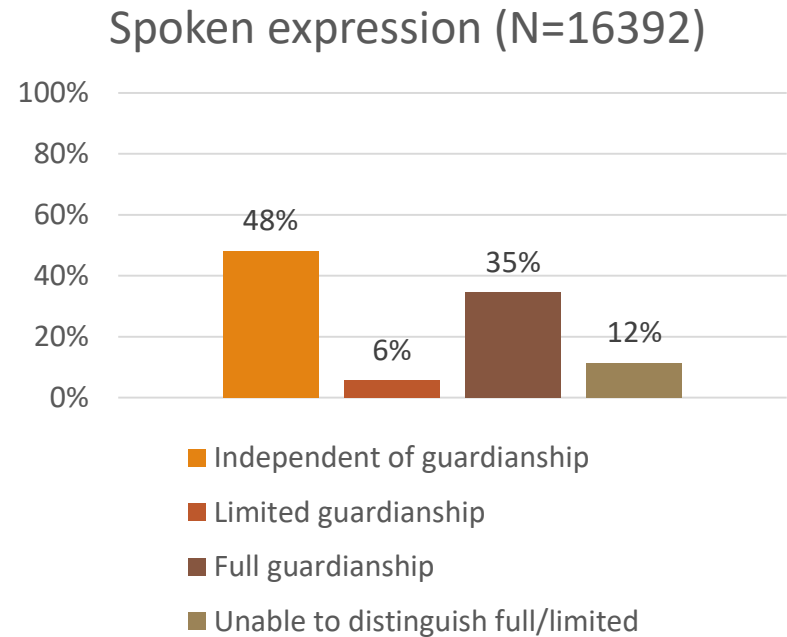
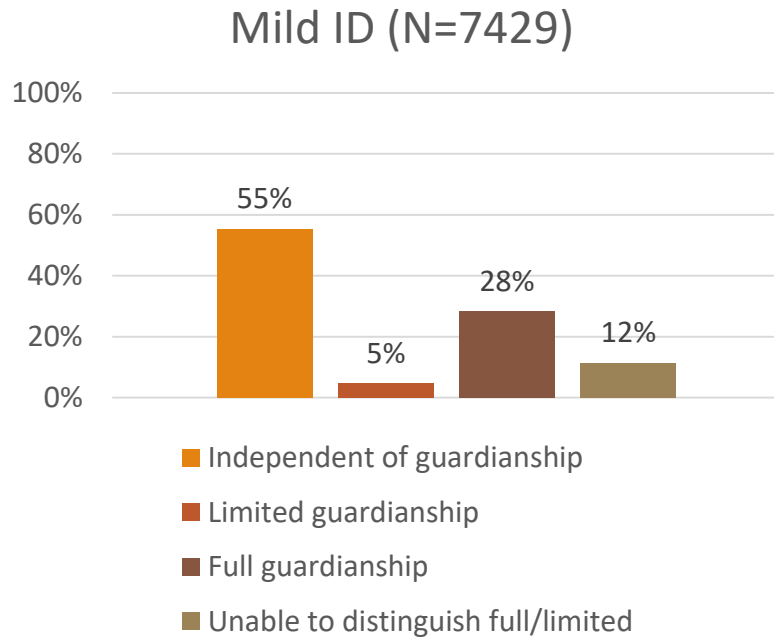
Check ONE.

- 1 No, person does not have a guardian/conservator (legally competent or presumed competent)
- 2 Yes, **limited** guardianship (a person has authority over certain decisions, such as entering into contracts, medical procedures, etc.)
- 3 Yes, **full** guardianship
- 4 Yes, **unable to distinguish** between limited or full guardianship
- 99 Don't know

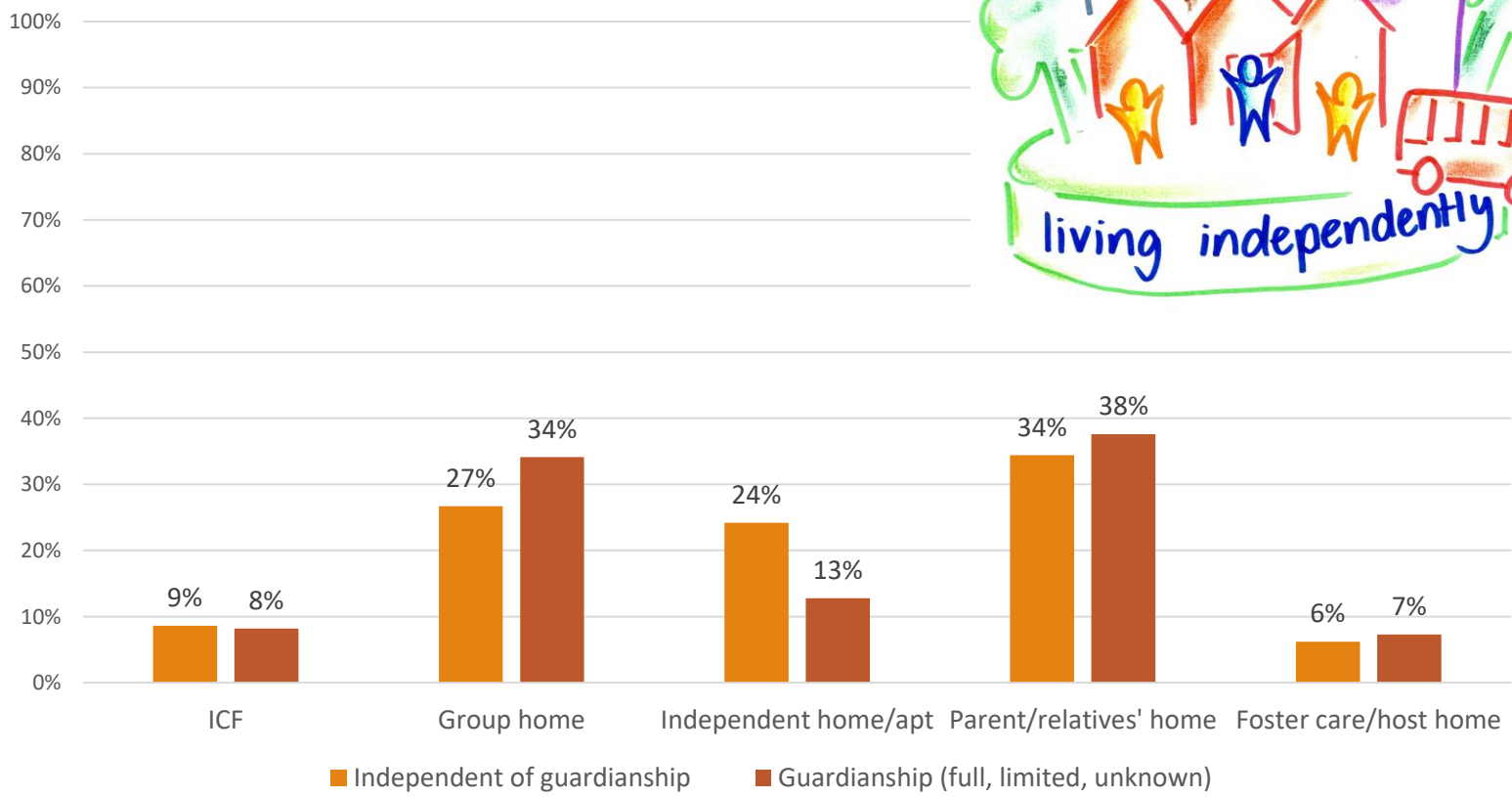
Total Sample (N=21,396)



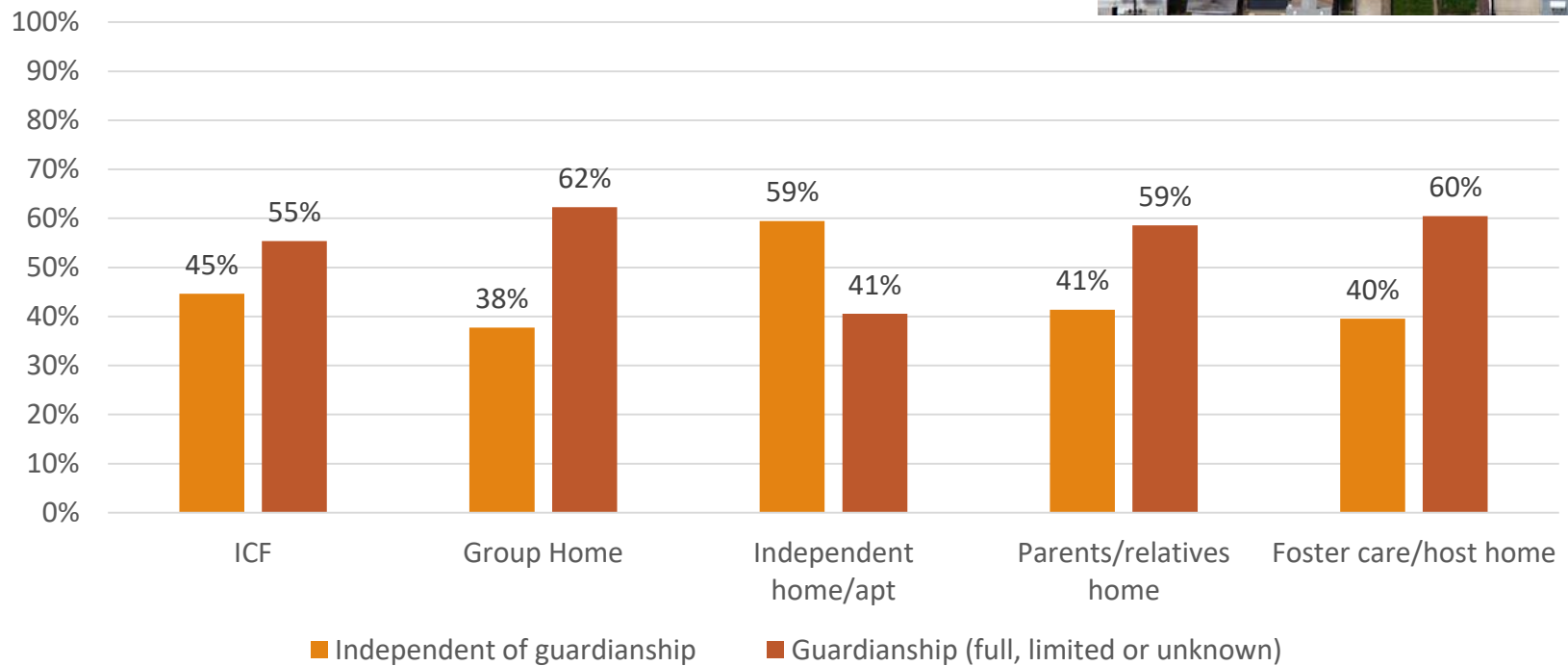
Characteristics of People with and Without Guardians



People with Full Guardianship Less Likely to Live Independently (N=20,610)

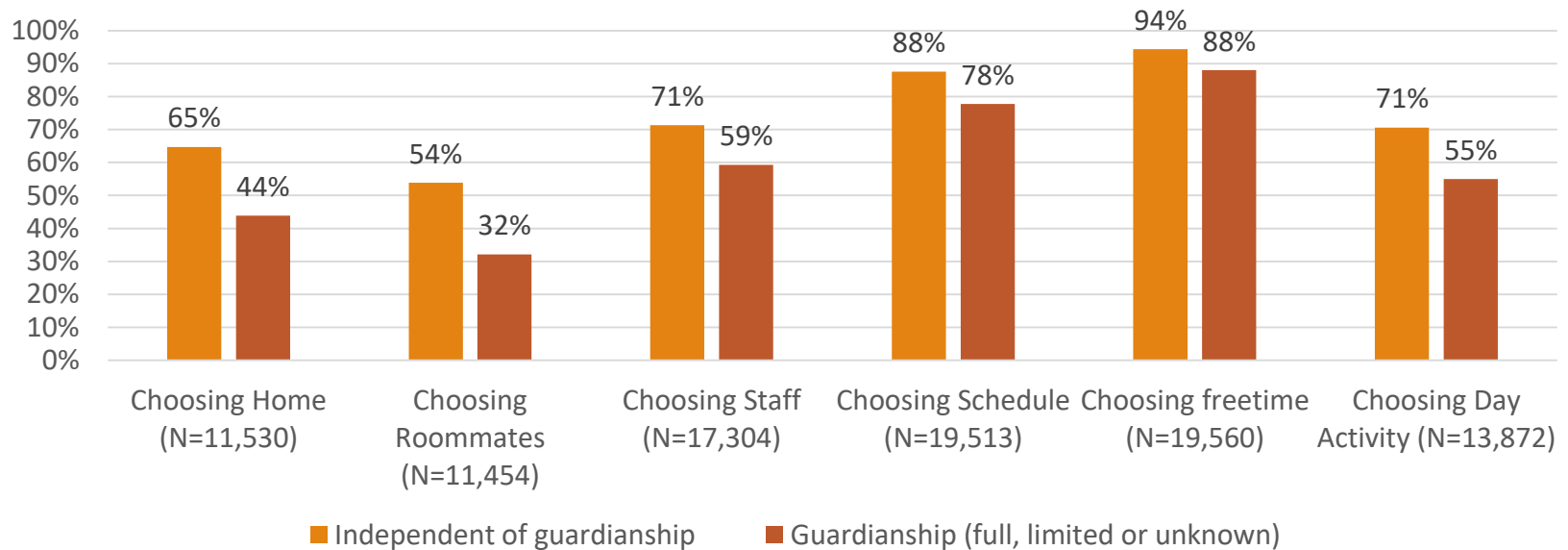


Of those in each residence type.....

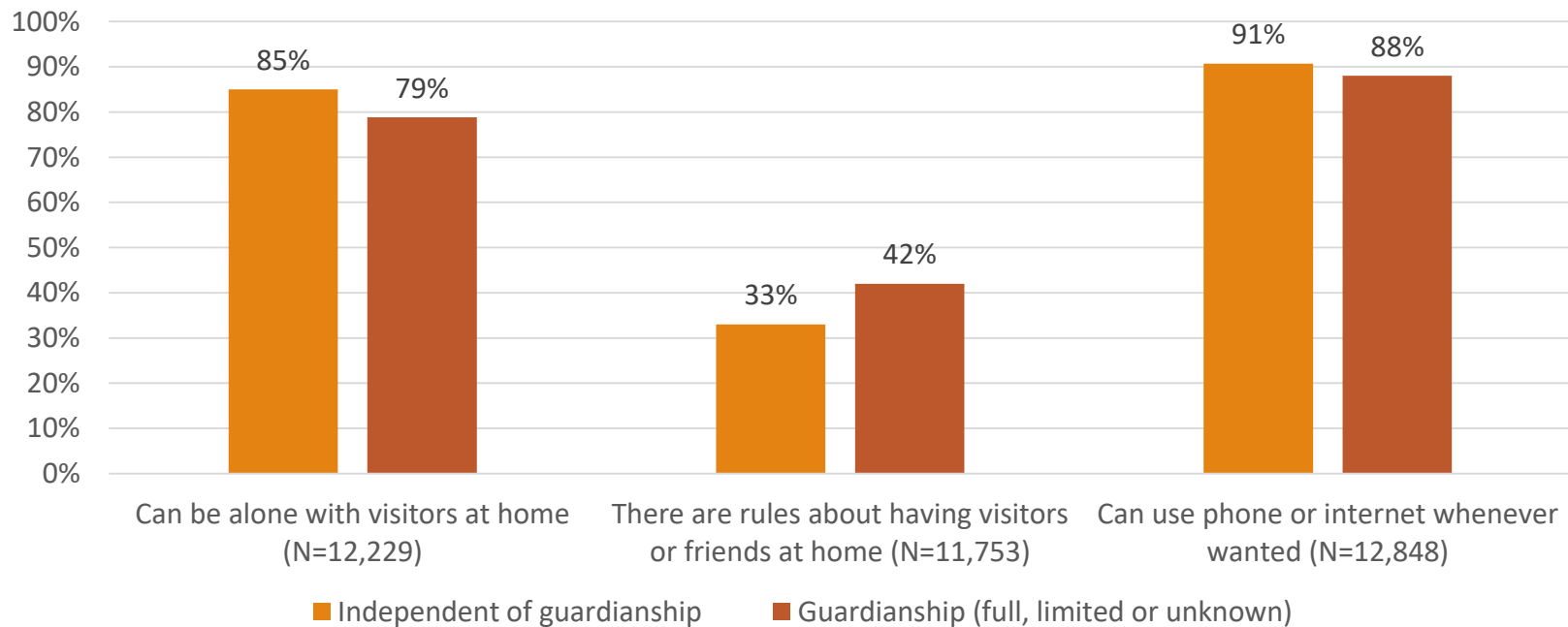


People with Full Guardians Less Likely to Make Choices

Person has at least some input in the following choices:



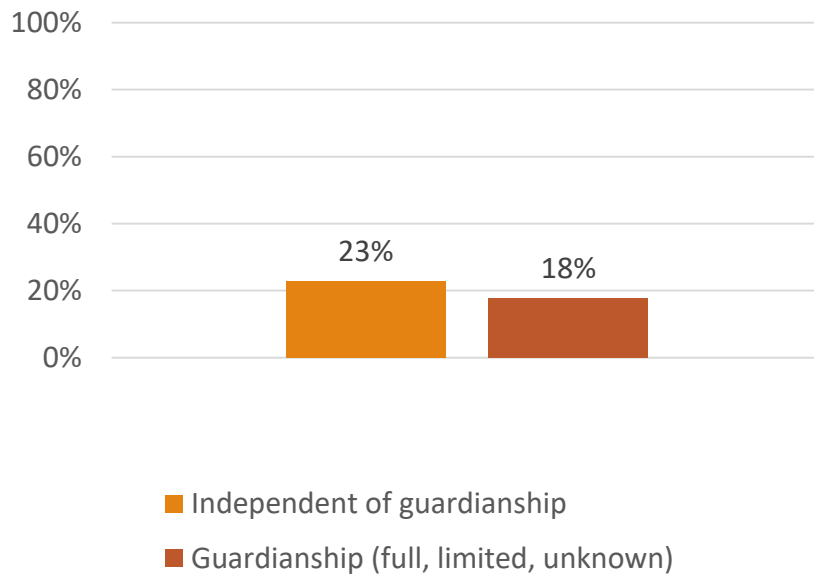
Rights and Respect



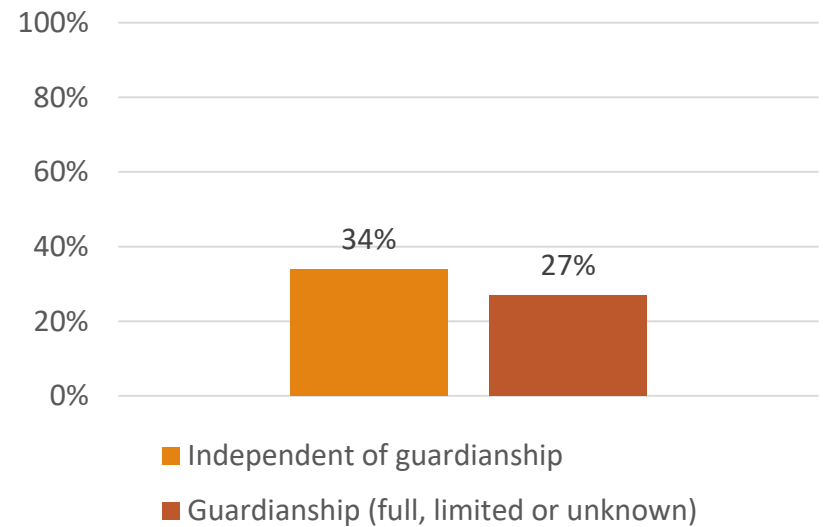
Employment



Is person in paid community job?
(N=19,722)



Is paid community job a goal in
person's service plan?
(N=19,359)



Relationships



	Independent of guardianship	Guardianship (full, limited or unknown)
Has friends (not staff or family)	79%	77%
Can go on a date (or is married/living with partner)	77%	67%
Has other ways of communicating with friends when cannot see them.	83%	77%



GUARDIANSHIP IS A BARRIER TO INDIVIDUAL
CHOICE

Summary



People without guardians are more likely to have:

Privacy rights respected to be alone with friends & visitors, use phone & internet freely

Input into choices of home, roommates, staff, daily schedule, what to buy with own money

Integrated job and goal of work in service plan

Friends who are not family or paid staff

Contact HSRI

Valerie Bradley

vbradley@hsri.org

617-876-0426 x 2319

617-876-0426 x 2307



Human Services
Research Institute

2336 Massachusetts Avenue

Cambridge, MA 02140

www.hsri.org

What did
she say?

