NATIONAL CORE INDICATORS

DISTRICT OF COLUMBIA DEPARTMENT on DISABILITY SERVICES

SUPPORTED DECISION MAKING

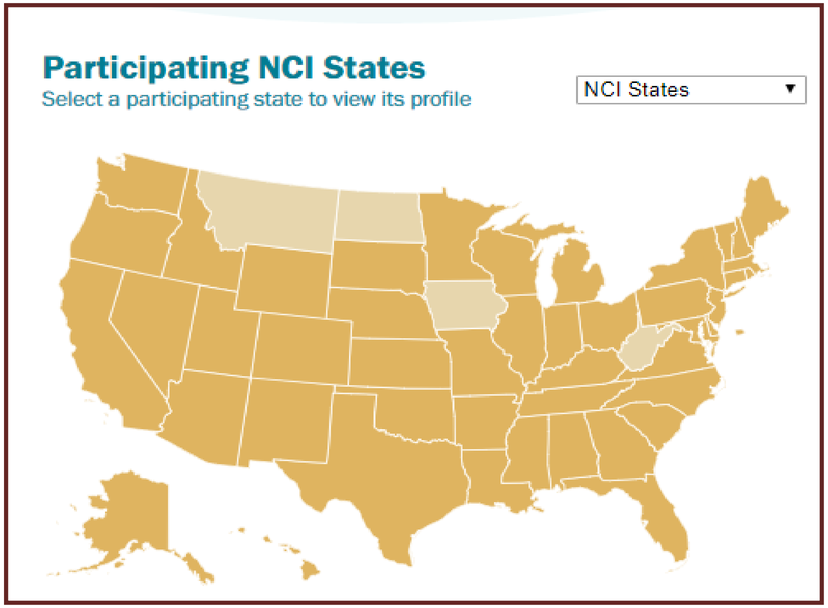
MARCH 2019

National Core Indicators

What are National Core Indicators?

National Core Indicators™ (NCI™) is a collaborative effort between the **National Association of State Directors of Developmental Disabilities Services (NASDDDS)** and the **Human Services Research Institute (HSRI)**.

The purpose of the program, which began in 1997, is to support NASDDDS member **agencies to gather a standard set of performance and outcome measures** that can be used to **track their own performance over time**, to **compare results across states**, and to **establish national benchmarks**.



Who Participates?

- NCI is **a voluntary activity** and **primarily state-funded**.
- **Fifteen states initially** stepped forward to work on the Core Indicators Project, as it was originally known, and pooled their resources to develop valid and reliable data collection protocols.
- **39 States plan to participate this year**

NCI Data Collection

In-Person Surveys

A **face to face** conversation completed with a **minimum of 400 persons who are 18 years of age or older** and **receiving at least one paid service from the state** (in addition to case management).

Family Surveys

- **The Adult Family Survey (AFS)** is mailed to families who have **an adult family member (age 18 and over) with I/DD living in their family's home**. The family member with I/DD must be receiving at least one service from the state DD agency, in addition to case management.
- **The Family/Guardian Survey (FGS)** is mailed to **family members or guardians of an adult (age 18 and over) with I/DD living outside of the family home**. The family member with I/DD must be receiving at least one service from the state DD agency, in addition to case management.
- **The Child Family Survey (CFS)** is mailed to families **who have a child (under age 18) with I/DD living in the family home**. The family member with I/DD must be receiving at least one service from the state DD agency, in addition to case management.

NCI Data Collection

Staff Stability

The **Staff Stability Survey** is an on-line survey of provider agencies supporting adults with ID/DD in residential, employment, day services and other in-home or community inclusion programs. The survey captures information about wages, benefits, and turnover of the direct care professional workforce, hired by agencies.

Agencies receive the survey through an email invitation (address provided by State) and agencies respond directly into ODESA.

This tool is not used for provider-level assessment as the data are de-identified and are reported aggregated at the state level.

GUARDIANSHIP

What is a Guardian?

A guardian is a **person, institution, or agency appointed by a court to manage the affairs and interests of another person**.

- **Full guardian** has plenary authority over an person's decisions— including crucial personal decisions such as where to live, what health care services or medical treatment to receive, as well as decisions about the person's financial matters, benefits, real estate, and other property.
- A court may also grant **limited guardianship** that extends to **specific decisions or legally binding agreements**, such as signing contracts or making decisions to assure financial obligations are met, or exclusively for medical decisions.

When does guardianship typically occur?

Guardianship is granted when evidence demonstrates that an **person lacks the capacity to make** some or all important life **decisions** and is therefore at **increased risk of harm**. Such incapacity is assumed to make the person vulnerable to risks such as financial exploitation.

Evidence does not justify removal of rights

The **preponderance of evidence may not always justify the removal of a person's rights** and **ability to direct their own life.**

Desire to Protect

The decision to place someone under guardianship is most often **motivated by a desire to protect the interests of the person with a disability**, but the consequences for that person may be profound.

GUARDIANSHIP

DISTRICT OF COLUMBIA DEPARTMENT on DISABILITY SERVICES

Who is Subject to Guardianship?

Adults with intellectual and developmental disabilities (IDD)—as well as **people with sensory disabilities, mental illness, traumatic brain injury, and challenges of aging**

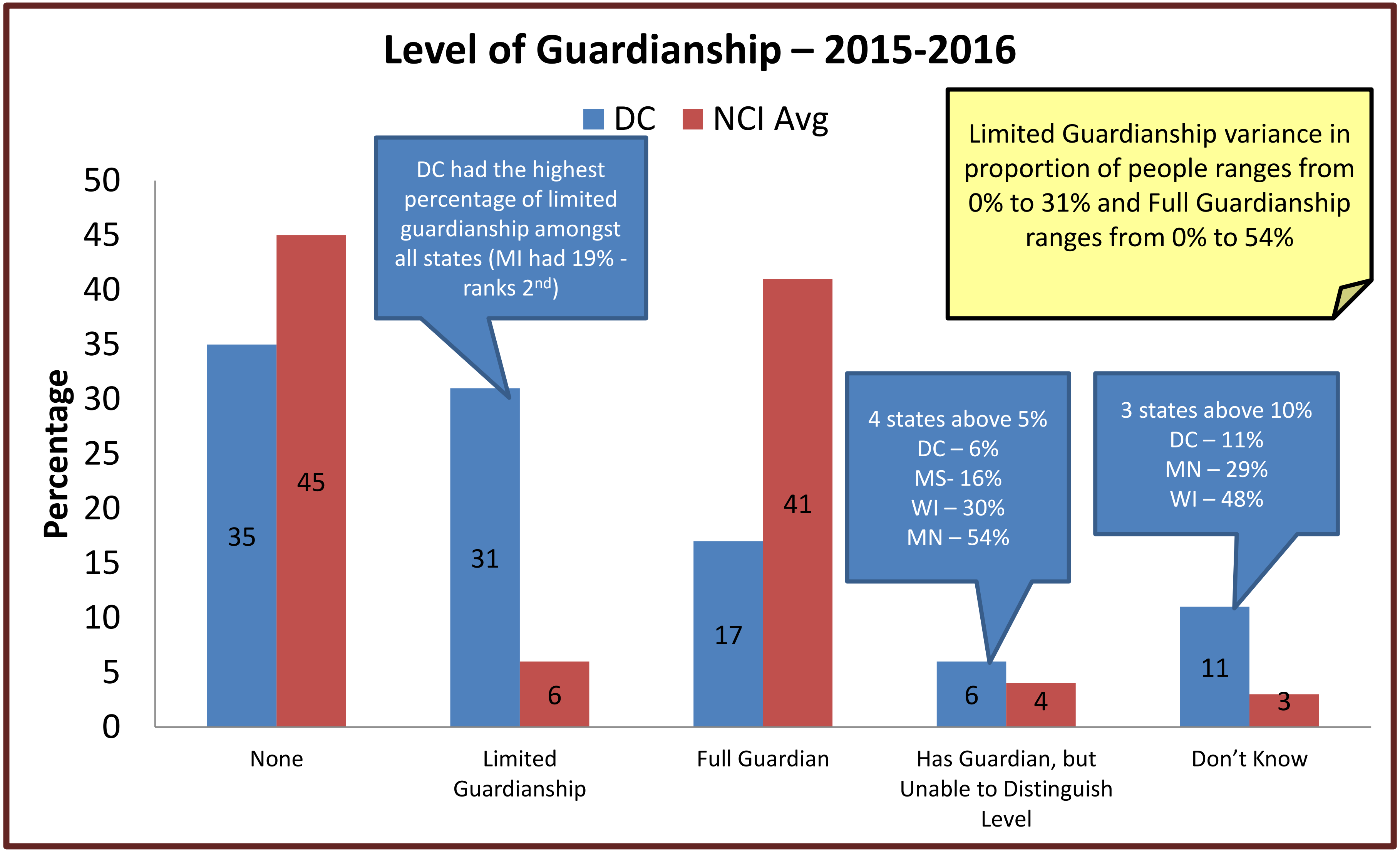
Potential Losses due to Guardianship

- 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., person service plan) because they must rely on others;
- When they want to make a purchase, get married, open a bank account or enter into a legal agreement, **people must ask permission**;
- They are deprived of the **"dignity of risk"** ;
- Doctors, dentists and other medical professionals **may not include the person in any treatment planning**

Impact on Quality of Life

- A person is denied the ability to be a causal agent in his/her life and often "**feels helpless, hopeless, and self-critical"**;
- "**Low self-esteem, passivity and feelings of inadequacy and incompetency**" associated with loss of autonomy and self-determination also result in decreased functioning;
- Being subject to guardianship **may affect subjective well-being including physical and mental health.**

DC Use of Guardianship



Level of Guardianship – 2015-2016

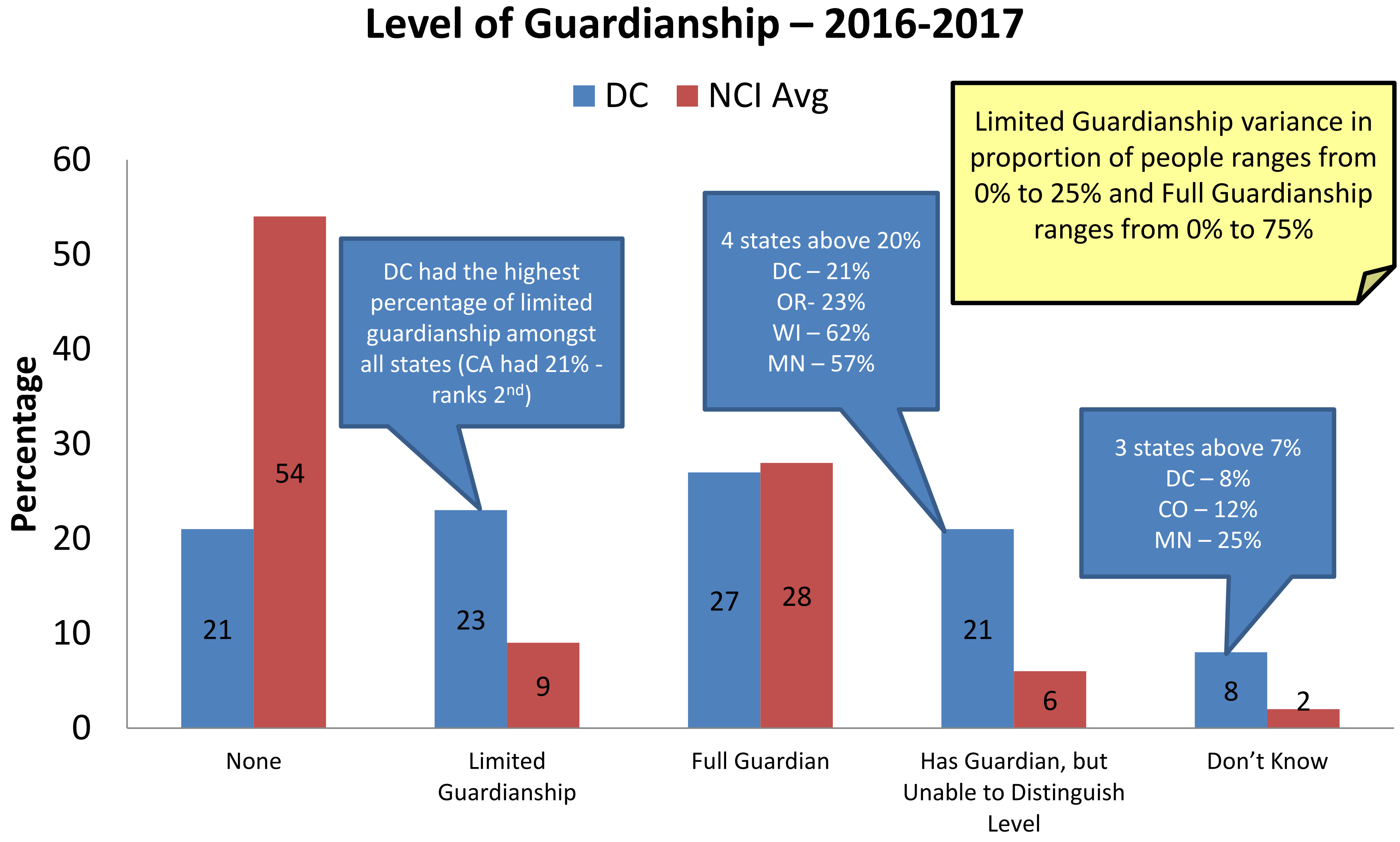
DC had the highest percentage of limited guardianship amongst all states (MI had 19% - ranks 2nd)

Limited Guardianship variance in proportion of people ranges from 0% to 31% and Full Guardianship ranges from 0% to 54%

4 states above 5%
DC – 6%
MS- 16%
WI – 30%
MN – 54%

3 states above 10%
DC – 11%
MN – 29%
WI – 48%

DC Use of Guardianship



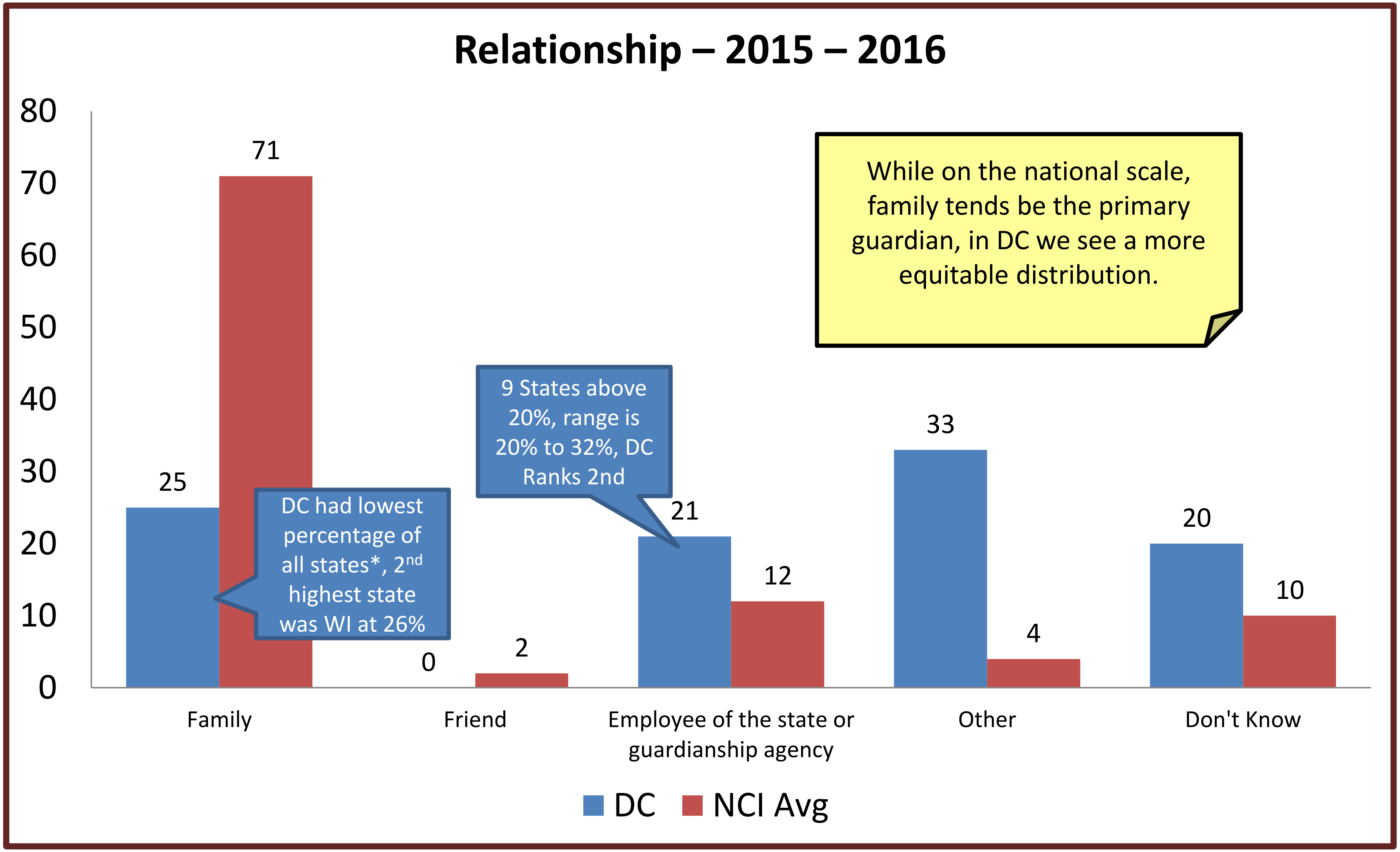
DC had the highest percentage of limited guardianship amongst all states (CA had 21% - ranks 2nd)

4 states above 20%
DC – 21%
OR- 23%
WI – 62%
MN – 57%

Limited Guardianship variance in proportion of people ranges from 0% to 25% and Full Guardianship ranges from 0% to 75%

3 states above 7%
DC – 8%
CO – 12%
MN – 25%

DC Guardian’s Relationship to Person

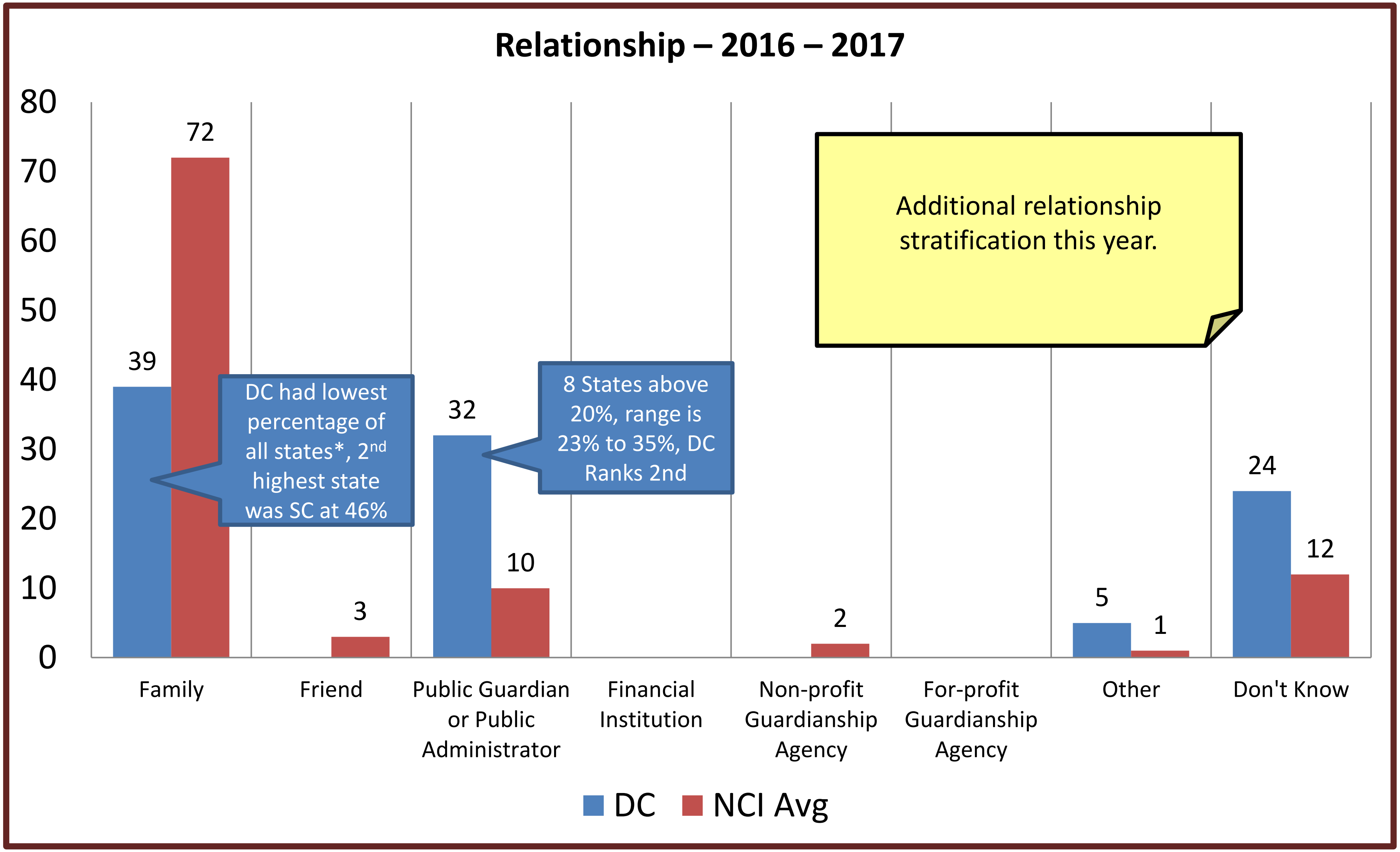


DC had lowest percentage of all states*, 2nd highest state was WI at 26%

9 States above 20%, range is 20% to 32%, DC Ranks 2nd

While on the national scale, family tends be the primary guardian, in DC we see a more equitable distribution.

DC Guardian’s Relationship to Person

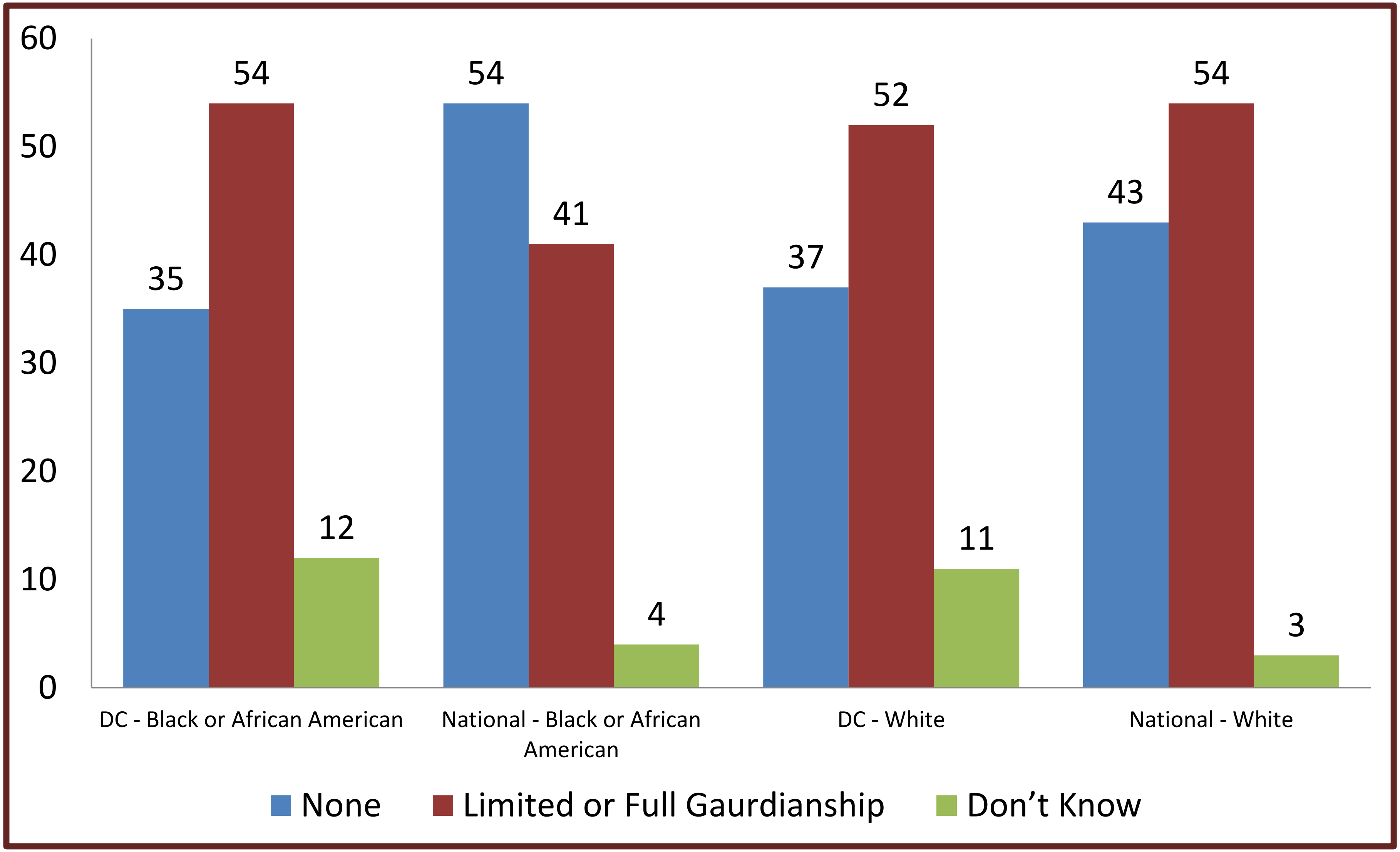


DC had lowest percentage of all states*, 2nd highest state was SC at 46%

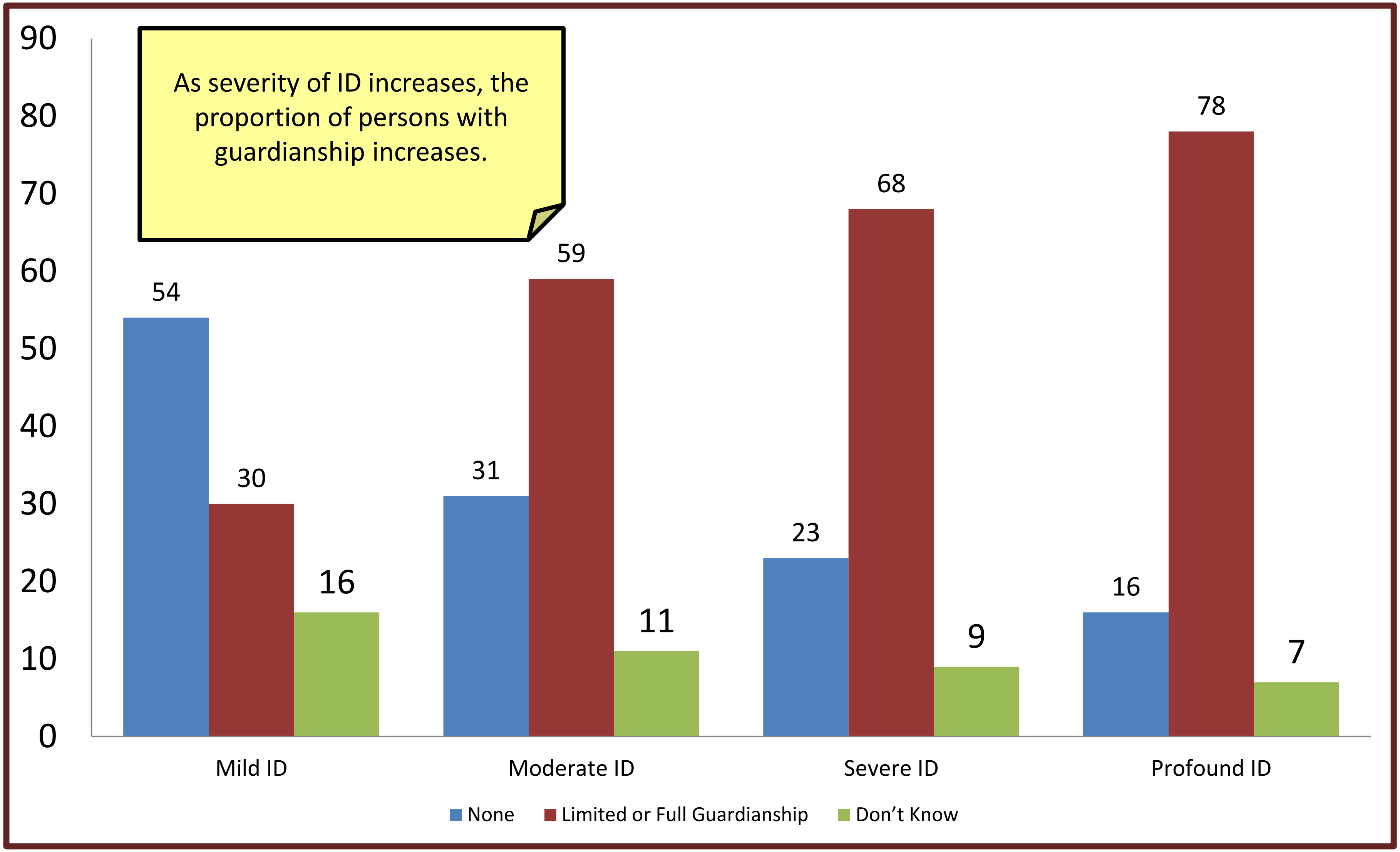
8 States above 20%, range is 23% to 35%, DC Ranks 2nd

Additional relationship stratification this year.

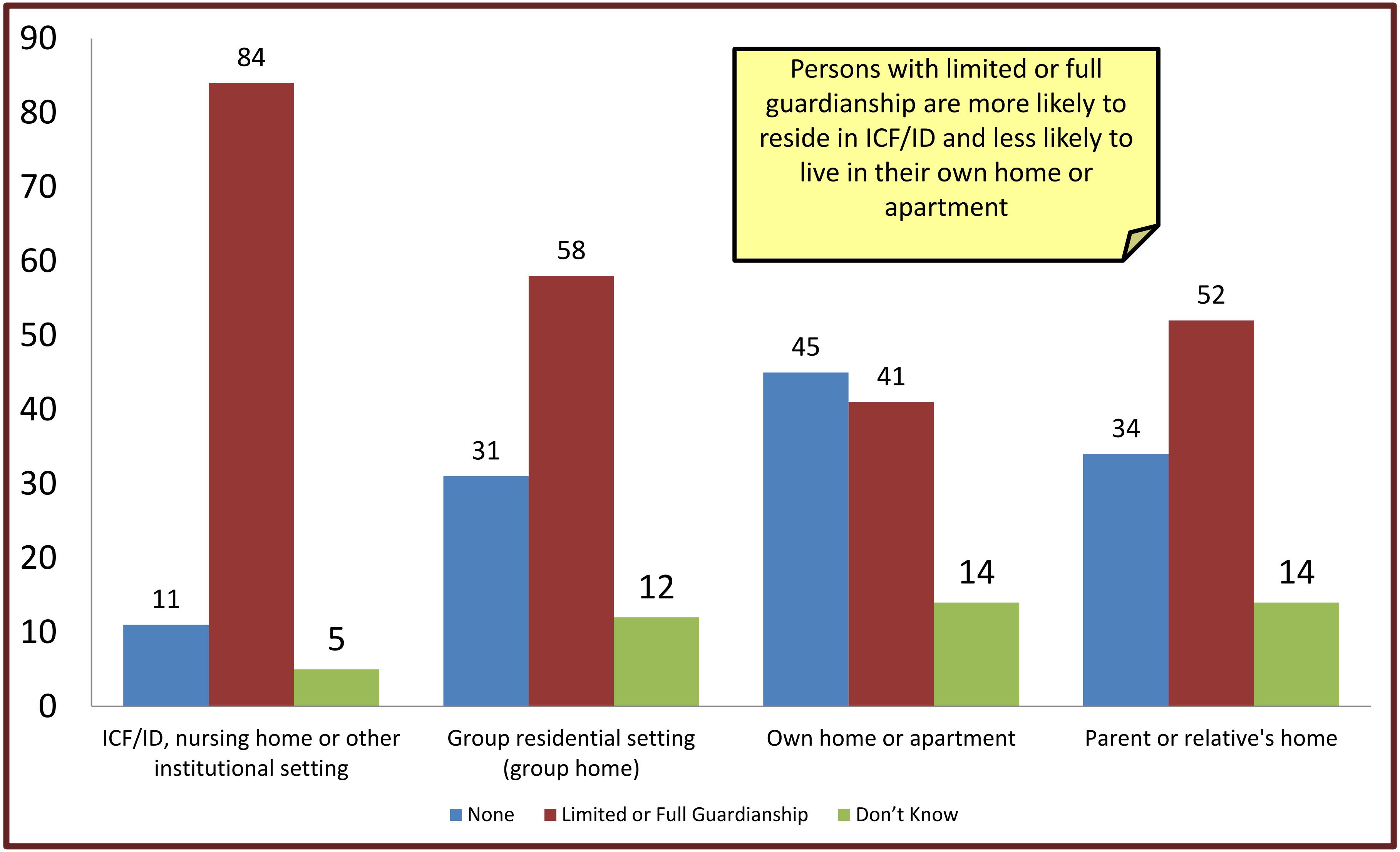
DC Guardianship Demographics



DC Guardianship ID Diagnosis

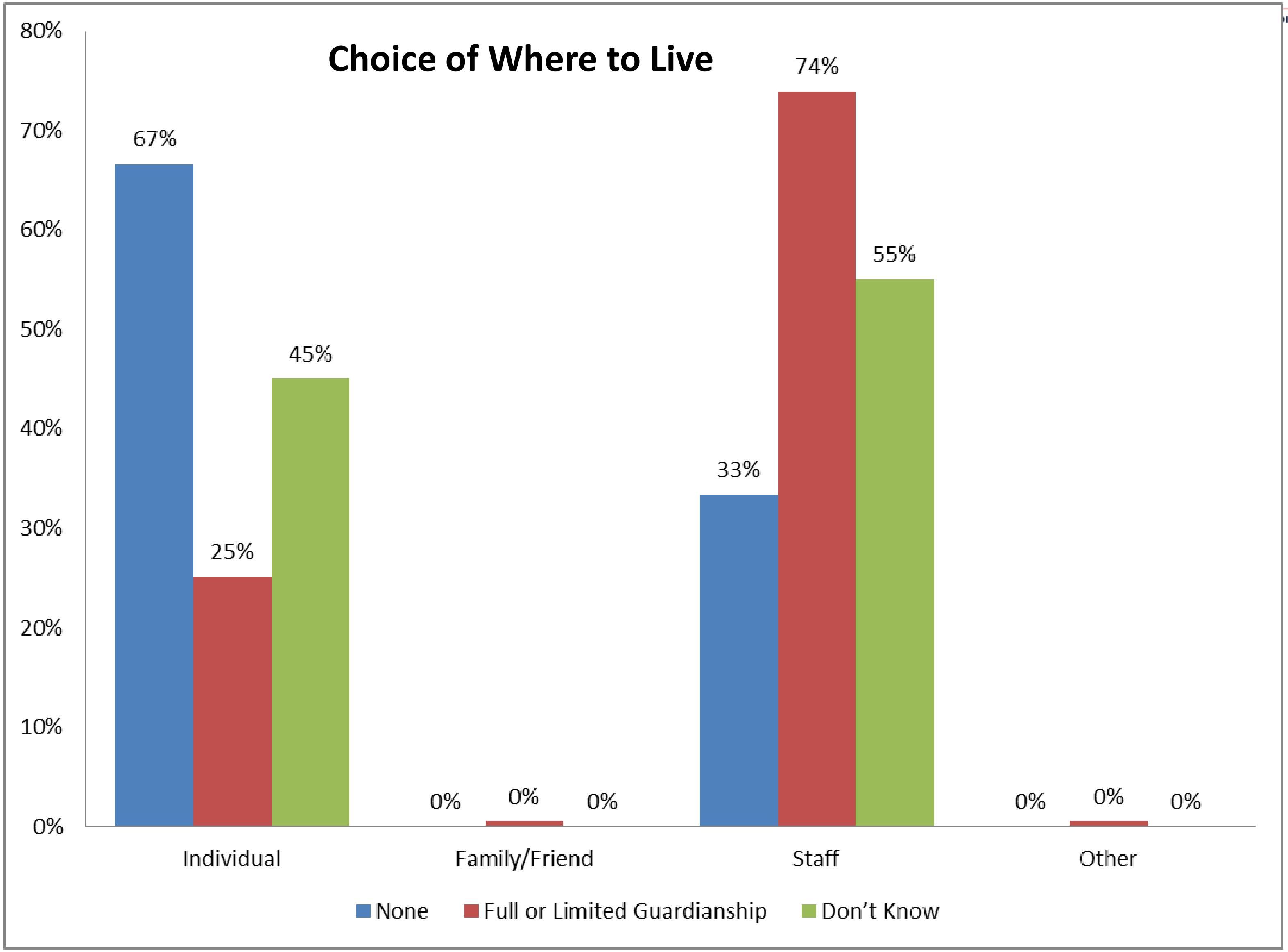

As severity of ID increases, the proportion of persons with guardianship increases.

DC Guardianship Residence Type

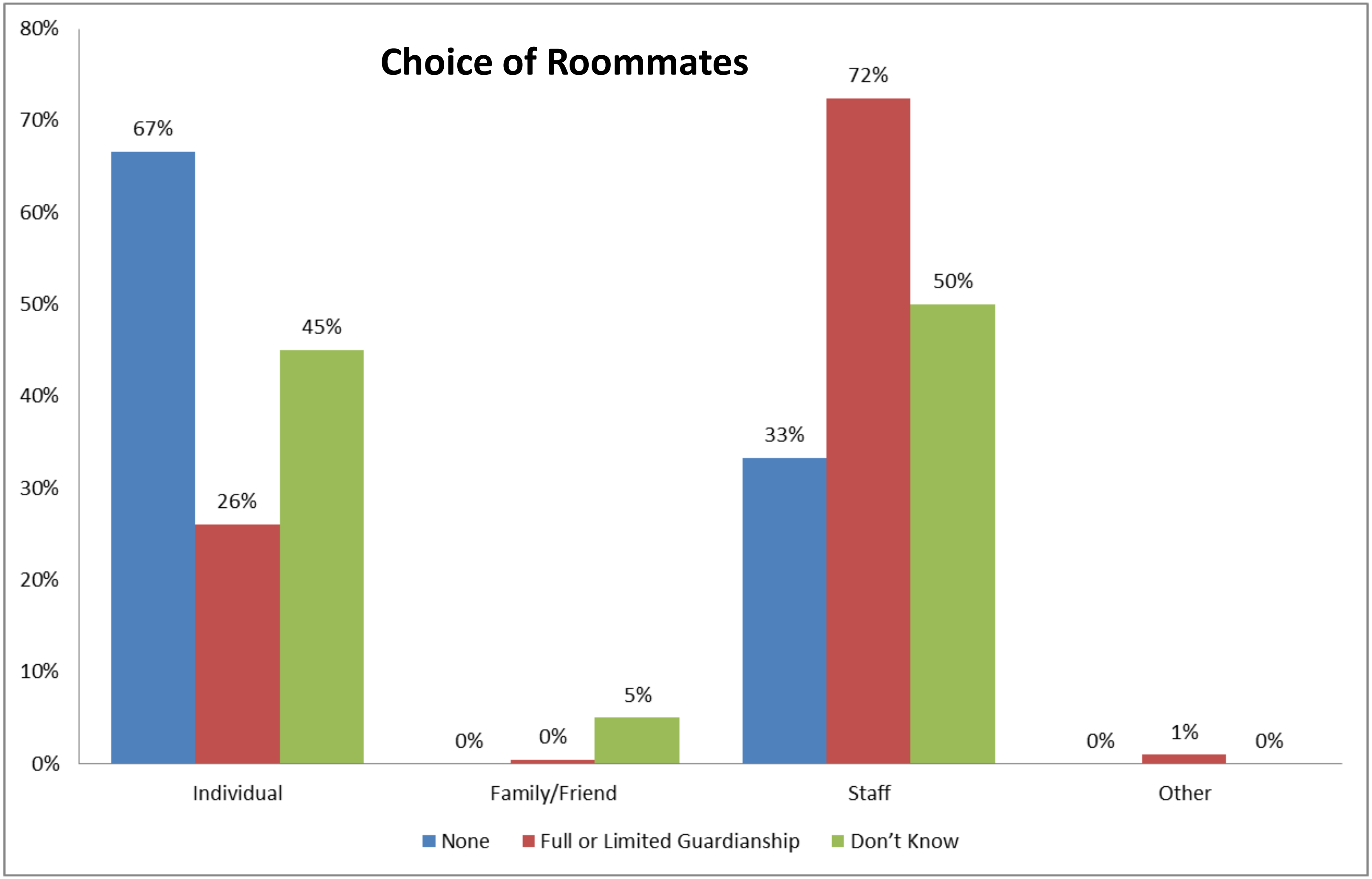


Persons with limited or full guardianship are more likely to reside in ICF/ID and less likely to live in their own home or apartment

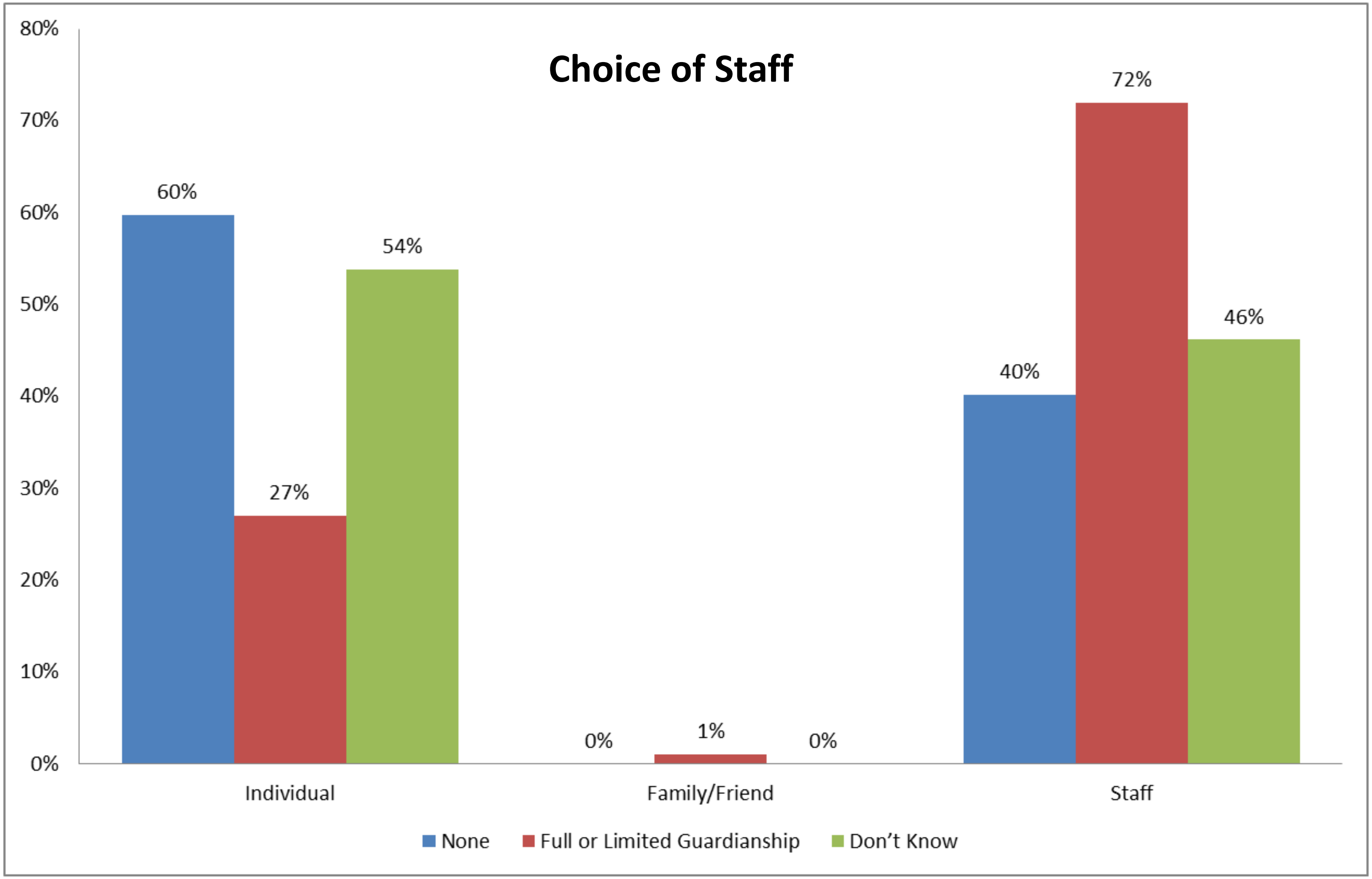
DC Guardianship – Choice of Home



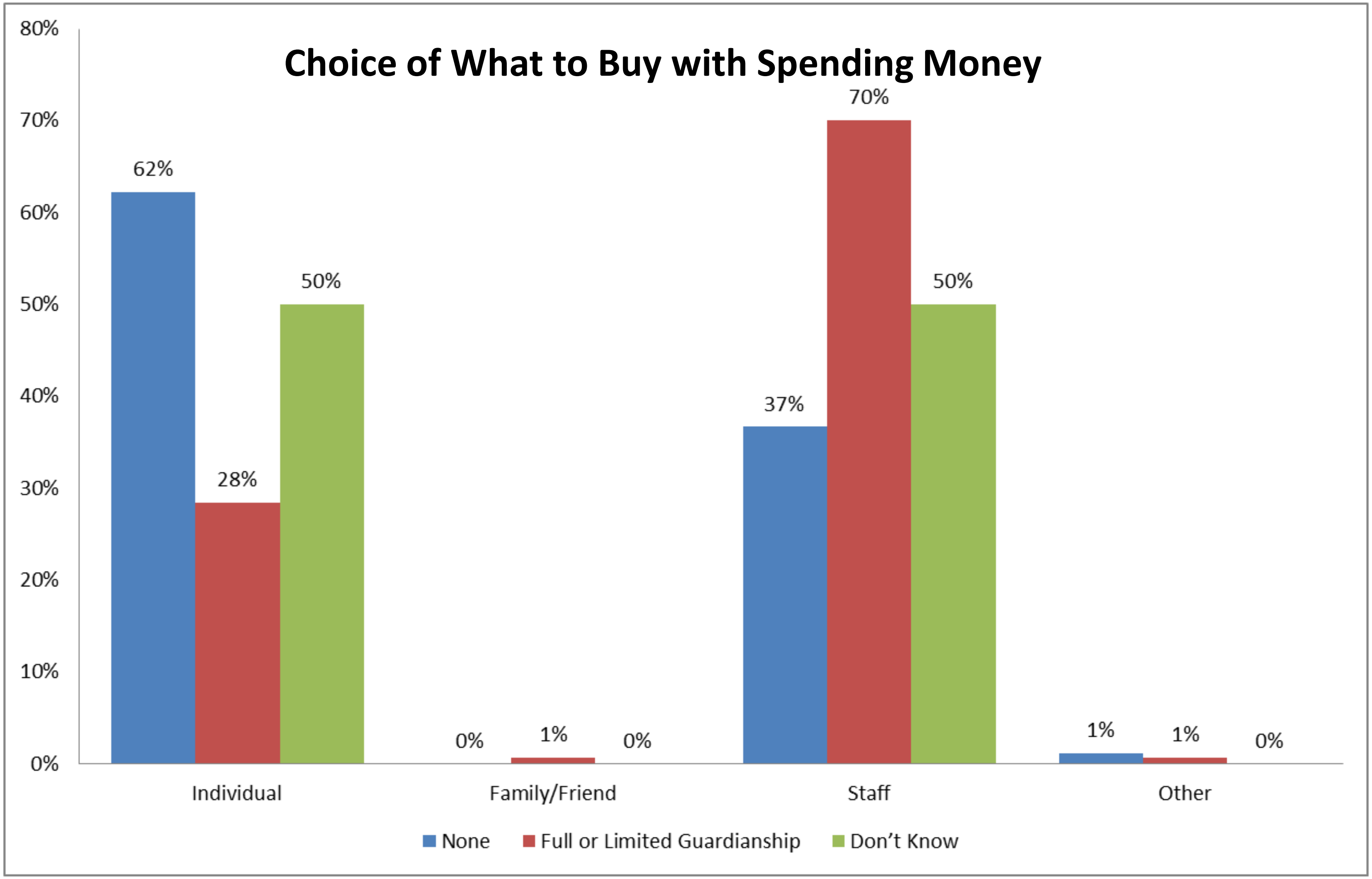
DC Guardianship – Choice of Roommates



DC Guardianship – Choice of Staff



DC Guardianship – Choice of What to Buy



Family Support Council - Supported Decision Making Project

Purpose: The Family Support Council convened two sessions for all stakeholders to give broad input into opportunities and perceived barriers to Supported Decision Making in DC, so that everyone: youth, adults, elders with disabilities, family members, service providers and agency staff will play a significant role in designing trainings and SDM rollout at key agencies in DC.

Recommendations from sessions:

1. DDS should design a "train the trainer" Supported Decision Making module in collaboration with pertinent key agencies in DC (to include: DC Health, Department of Health Care Finance, Child and Family Services Agency, District of Columbia Public Schools, Department of Behavioral Health, and District of Columbia Office on Aging, Aging and Disability Resource Center) in the next 12 months, and the training should utilize the stakeholder questions and discussion from the FSC-Supported Decision Making Project focus group sessions, the PowerPoint presentation developed by Quality Trust from the January 24th group session (with author credit to Quality Trust for reference) and utilize stakeholders as possible trainers.
2. DDS should develop a plan for annual marketing/communications with various groups about Supported Decision Making – to include: DC agencies, financial institutions, medical facilities/providers, and other community organizations.
3. DDS should provide periodic reports to the Family Support Council about the implementation of recommendations #1-2 through June 2020.

ADDITIONAL RECOMMENDATIONS BASED ON DATA?