

# National Core Indicators™

Sarah Taub Webinar Series:

Guardianship  
July 23, 2019





# Sarah Taub

Sarah Taub was the National Core Indicators Director until 2013 when her life was cut short by an aggressive cancer.

Her sense of mission and purpose was an essential part of the growth of NCI to the prominence it has today.

She was a fierce advocate for people with disabilities, and for their representation at all levels in the work we do. She never let us forget the people behind the numbers.

# Agenda

1

What is  
Guardianship?

2

What do NCI Data  
show about people  
in guardianship?

3

One state's  
experiences: MO

Presenter:

Jane St. John  
Training and Development  
Specialist at the UMKC  
Institute for Human  
Development

4

One state's  
experiences: DC

Presenters:

Rebecca Salon  
Program Specialist in the  
State Office of Policy,  
Planning and Innovation

Aman Sanghera  
Performance Management  
Manager in the the State  
Office of Policy, Planning  
and Innovation



# WHAT IS 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 individual.
- The National Guardianship Association (NGA) suggests that the most prudent use of guardianship occurs
  - “when a person can no longer make or communicate safe or sound decisions about his/her person and/or property or has become susceptible to fraud or undue influence.”
- Guardian may make decisions on:
  - Where to live, health treatment or medical care
  - Financial matters, benefits, real estate and other property
  - Limited guardianship: certain decisions/legally binding agreements



# The NGA recommends guardians practice with the “highest allegiance to the person.”

- The decision to place someone under guardianship is most often motivated by a desire **to protect the interests of the individual with a disability**
  - but the consequences for that individual may be profound.
- When a guardian’s decision substitutes for that of the individual with IDD, the following losses may result:
  - 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 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.

# Effects of guardianship

- Research on the negative impact of the imposition of guardianship on the quality of life of the individual indicates:
  - 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.

Deci, E. (1975). *Intrinsic motivation*. New York, NY: Plenum Press.

Winick, B. (1995). The side effects of incompetency labeling and the implications for mental health law. *Psychology, Public Policy and Law*, 1(1), 6–42.  
<http://dx.doi.org/10.1037//1076-8971.1.1.6>

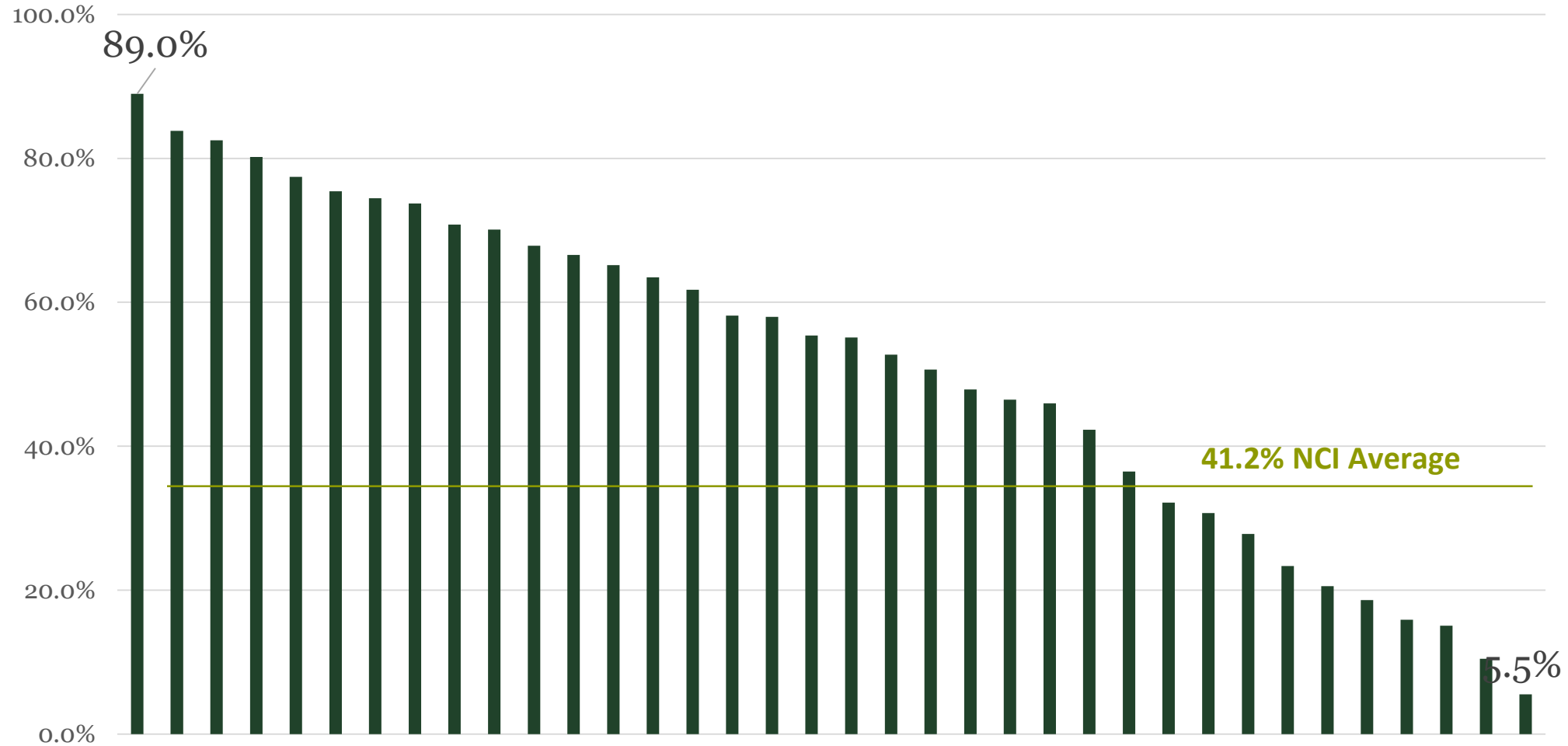
Wright, J. (2010). Guardianship for your own good: Improving the well-being of respondents and wards in the USA. *International Journal of Law and Psychiatry*, 33(5–6), 350–368. <http://dx.doi.org/10.1016/j.ijlp.2010.09.007>

# WHAT DO NCI DATA REVEAL ABOUT THE GUARDIANSHIP STATUS OF PEOPLE WITH IDD?



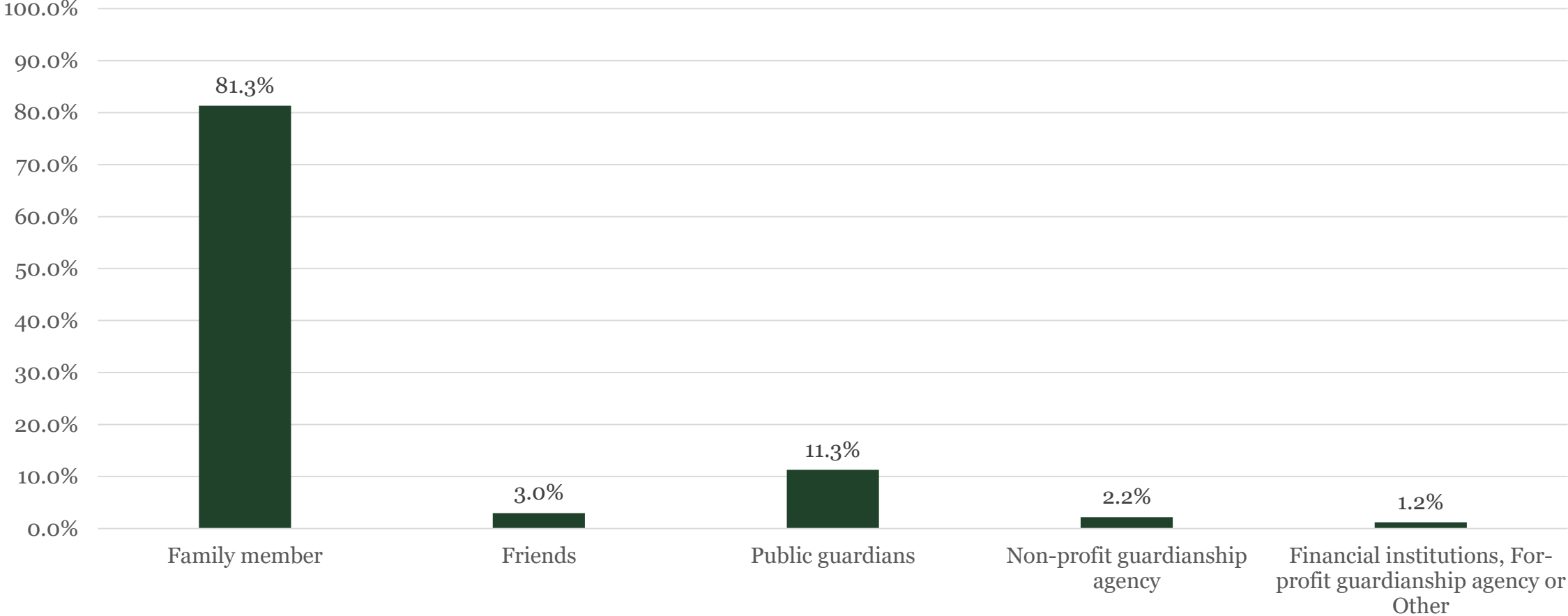


# Percentage of respondents with guardianship by state (Full, limited or unknown level)

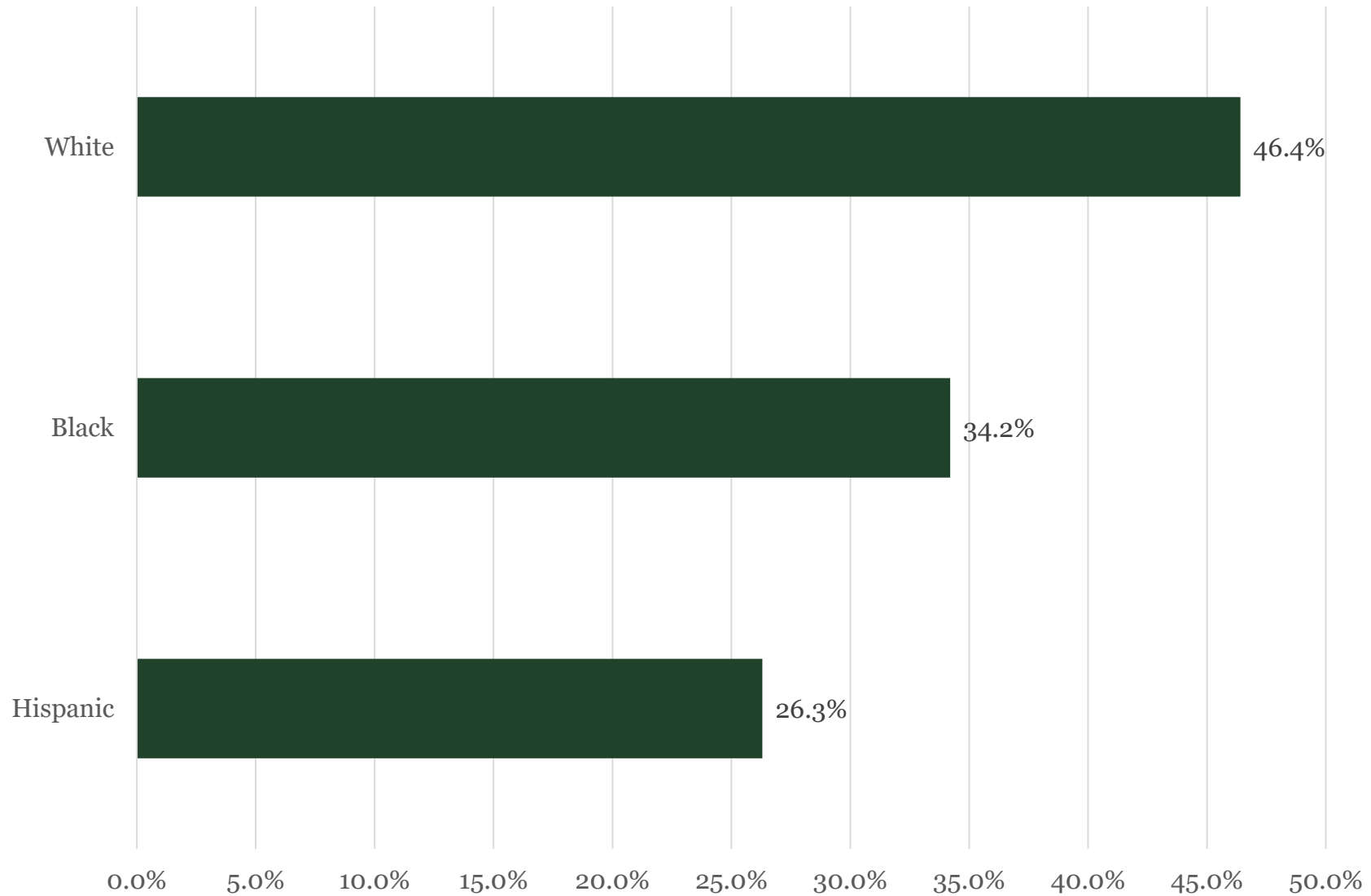


All relationships shown in this presentation are significant at the  $p \leq .001$  level. Data are not weighted. Total sample: 25,671 respondents from 36 states including DC. Averages are averages of cases (not averages of state averages).

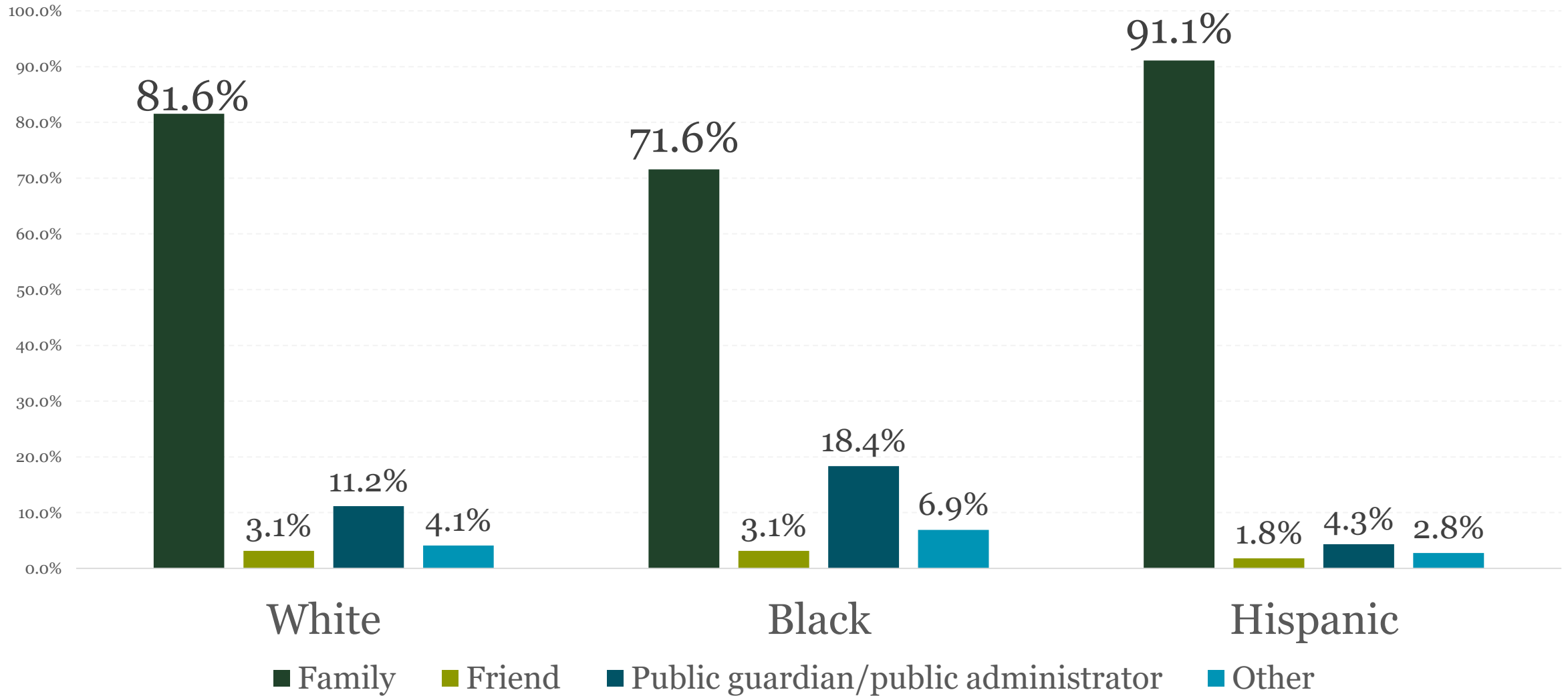
# Of those with guardianship, who serves as guardian?



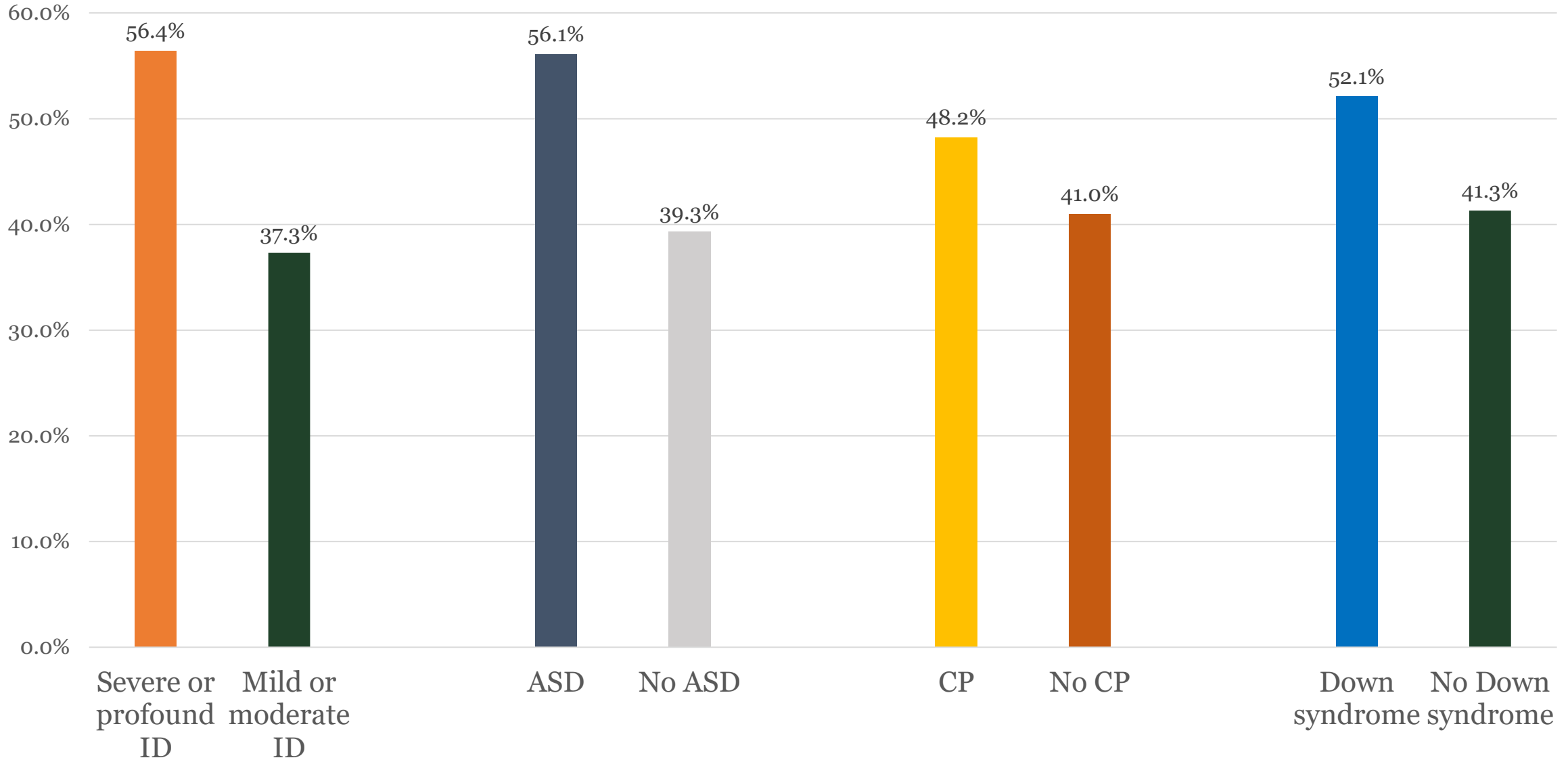
# Guardianship by race



# Relationship of the guardian to the person receiving supports



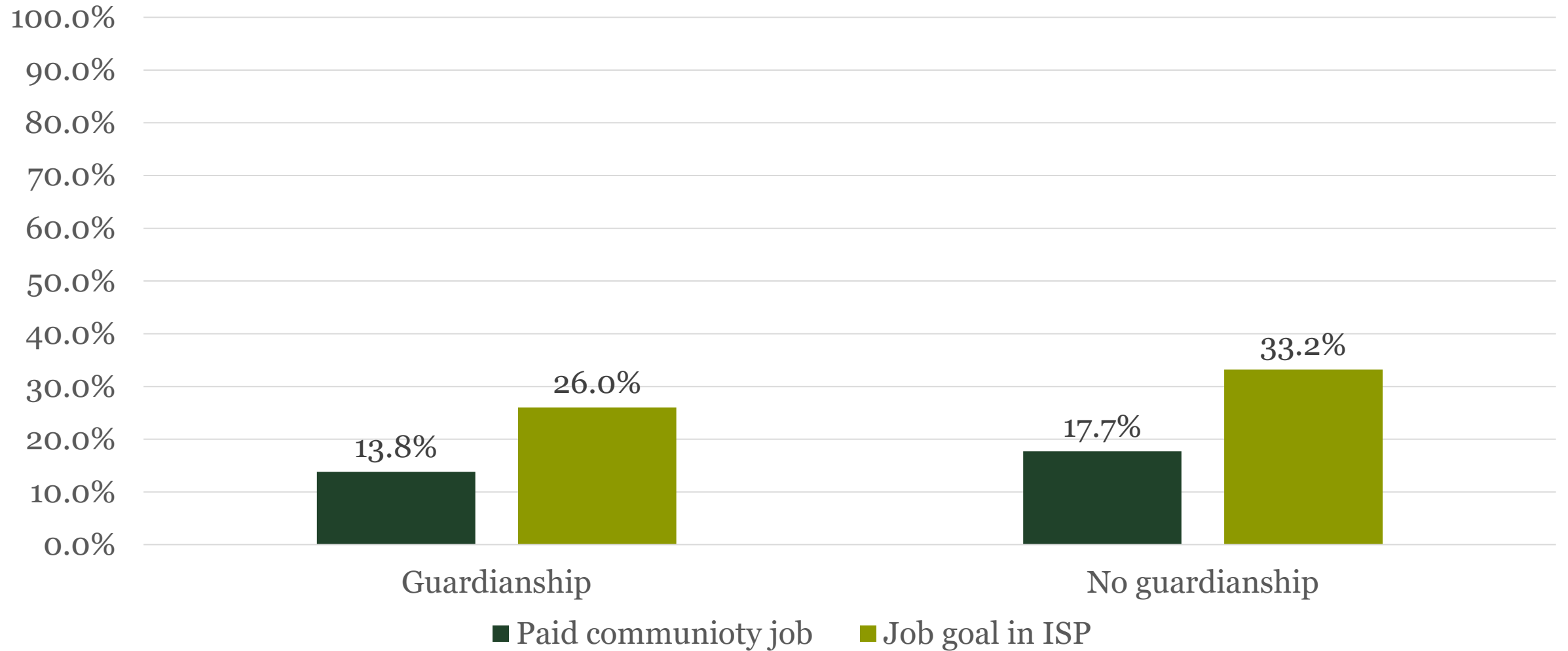
# Guardianship by diagnosis (co-occurring with ID)



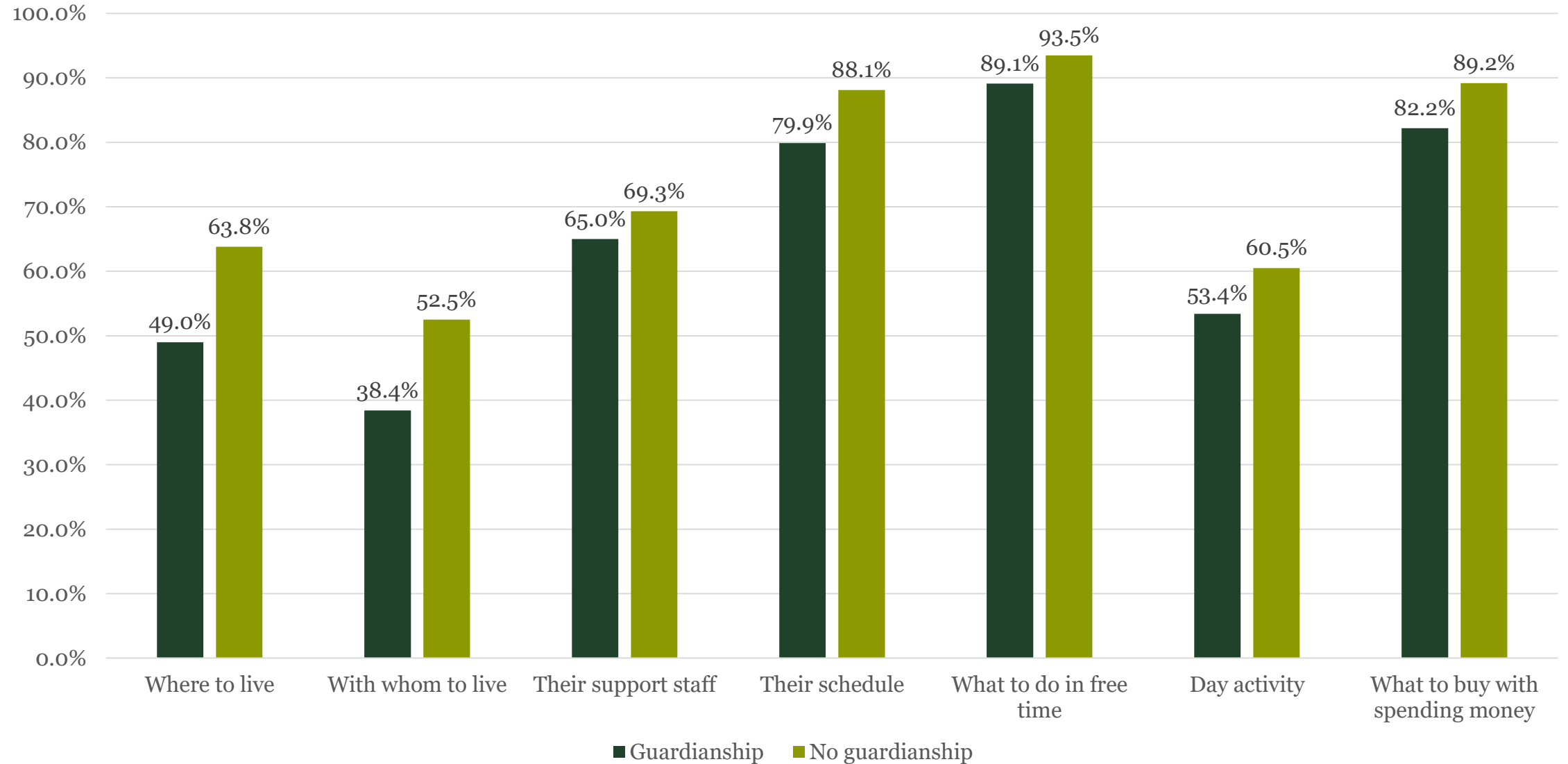
# Guardianship by residence type

	ICF/IID, NURSING FACILITY OR OTHER INSTITUTIONAL SETTING	GROUP RESIDENTIAL SETTING (E.G., GROUP HOME)	OWN HOME / APARTMENT	PARENT'S OR RELATIVE'S HOME	FOSTER CARE OR HOST HOME
<b>No Guardianship</b>	5.8%	28.0%	23.9%	38.3%	4.0%
<b>Guardianship (limited, full, or unknown level)</b>	5.8%	31.9%	13.3%	42.5%	6.6%

# Employment



# Input in choices, by guardianship





# Summary

## Respondents with guardians are less likely to:

- Live in their own homes or apartments and are more likely to live in group homes
- Be involved in making choices about their lives
- Be included in their community
- Have their rights respected
- Have community jobs or service plans with this goal
- Be supported to communicate with friends
- Be able to go on dates
- Be married