

National Core Indicators Adult Family & Family Guardian Surveys Findings from 2014-15

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Research Institute

Who responds to these mail surveys?

Adult Family Survey

- Family member who *lives with* adult with I/DD receiving services.
- Referred to as “In home”

Family Guardian Survey

- Family member or guardian who *does not live with the adult* with I/DD receiving services.
- Referred to as “out home”





What do Florida's
NCI Adult Family
and Family Guardian
surveys have to say
about the HCBS
service planning &
setting
requirements?



SERVICE PLANNING & EXERCISING CHOICE

HCBS rules require:

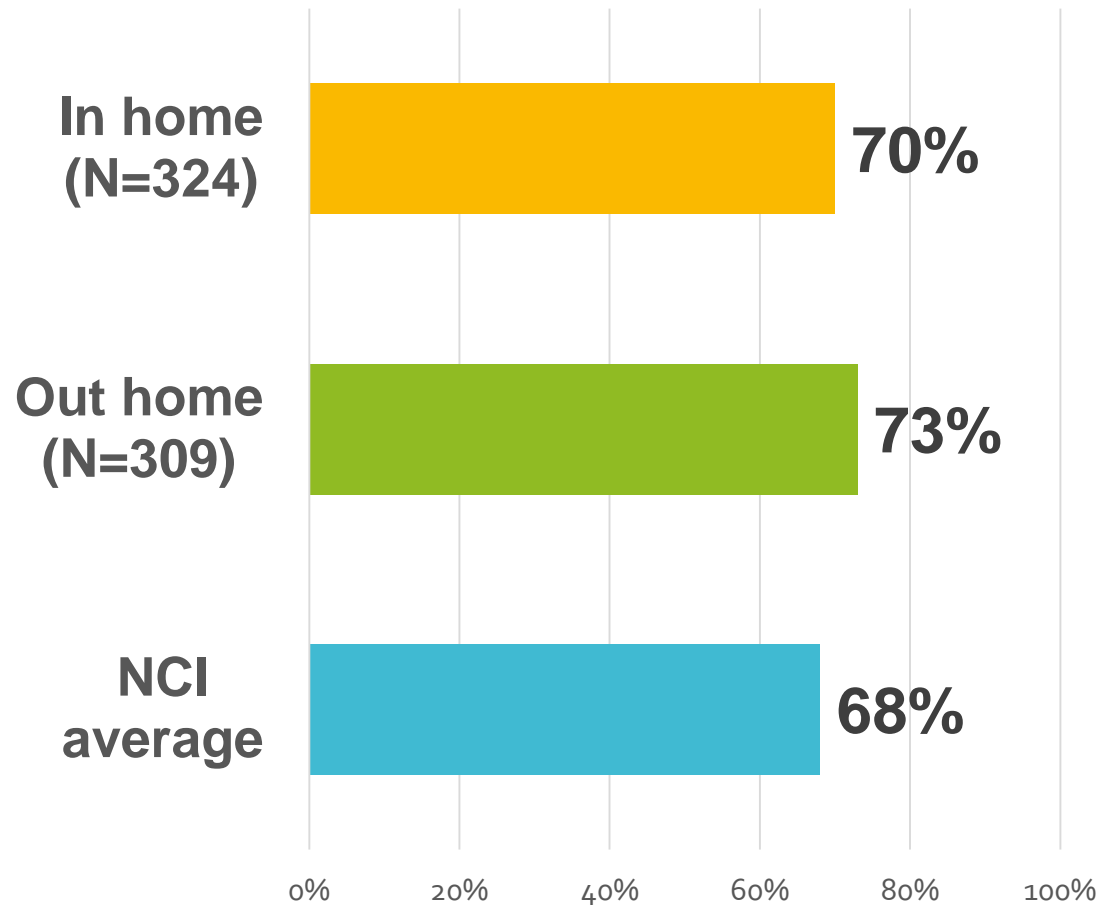
- ✓ Person centered service planning
- ✓ Choice of services and supports, including option of generic services and supports
- ✓ Choice of who provides services





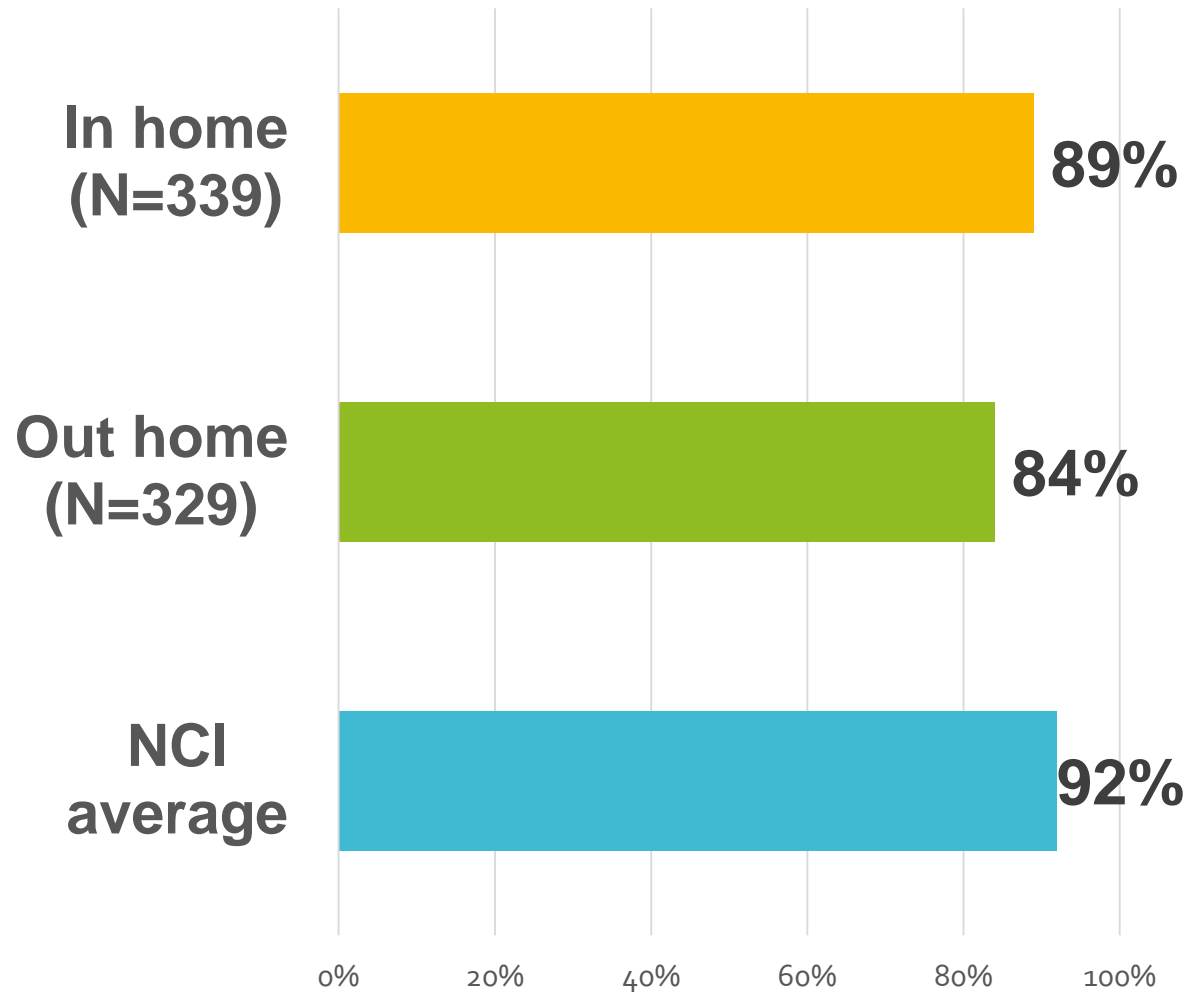
Person receiving services was involved in developing service plan

Person centered planning requires individual's involvement in service planning





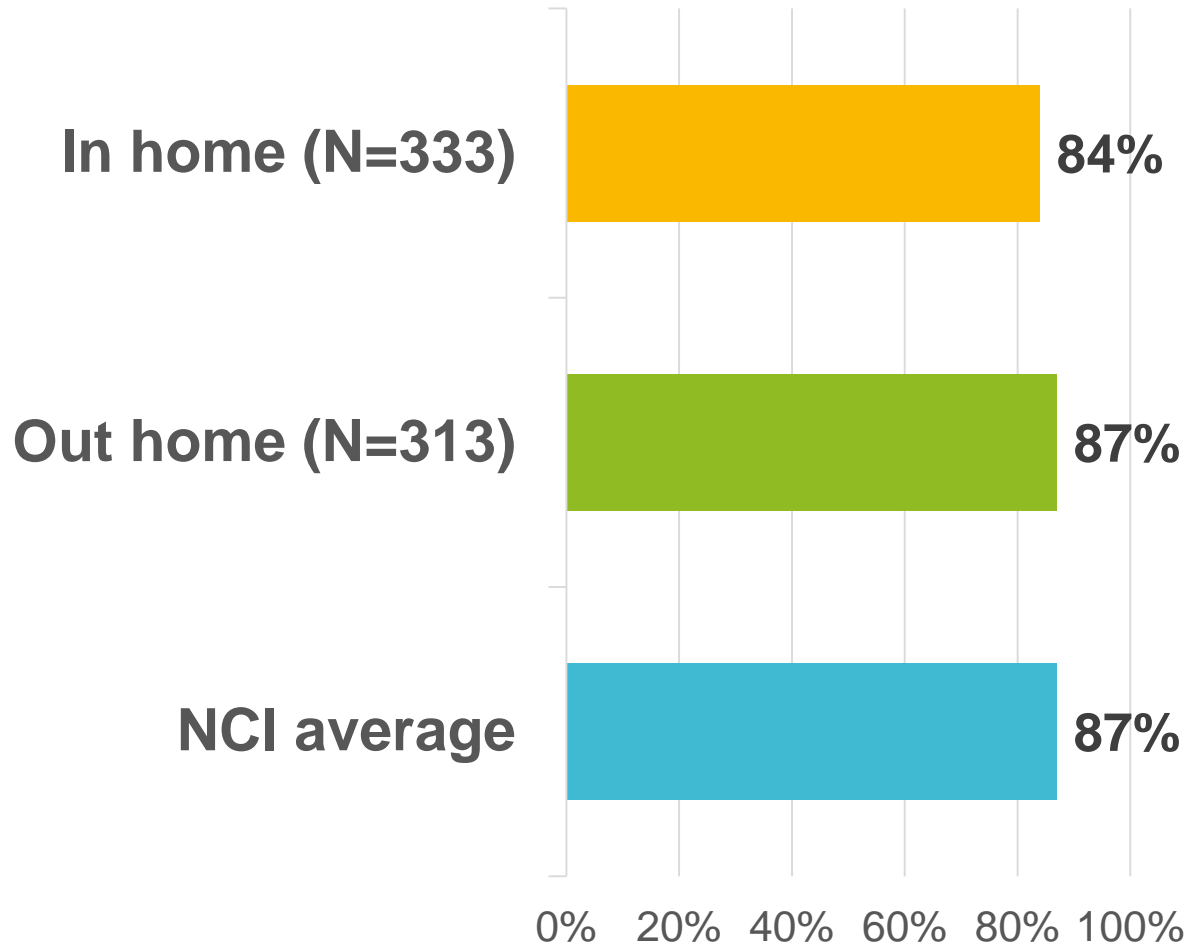
Family or Guardian was involved in developing the service plan





Service plan has **ALL** services & supports the person receiving services **WANTS**

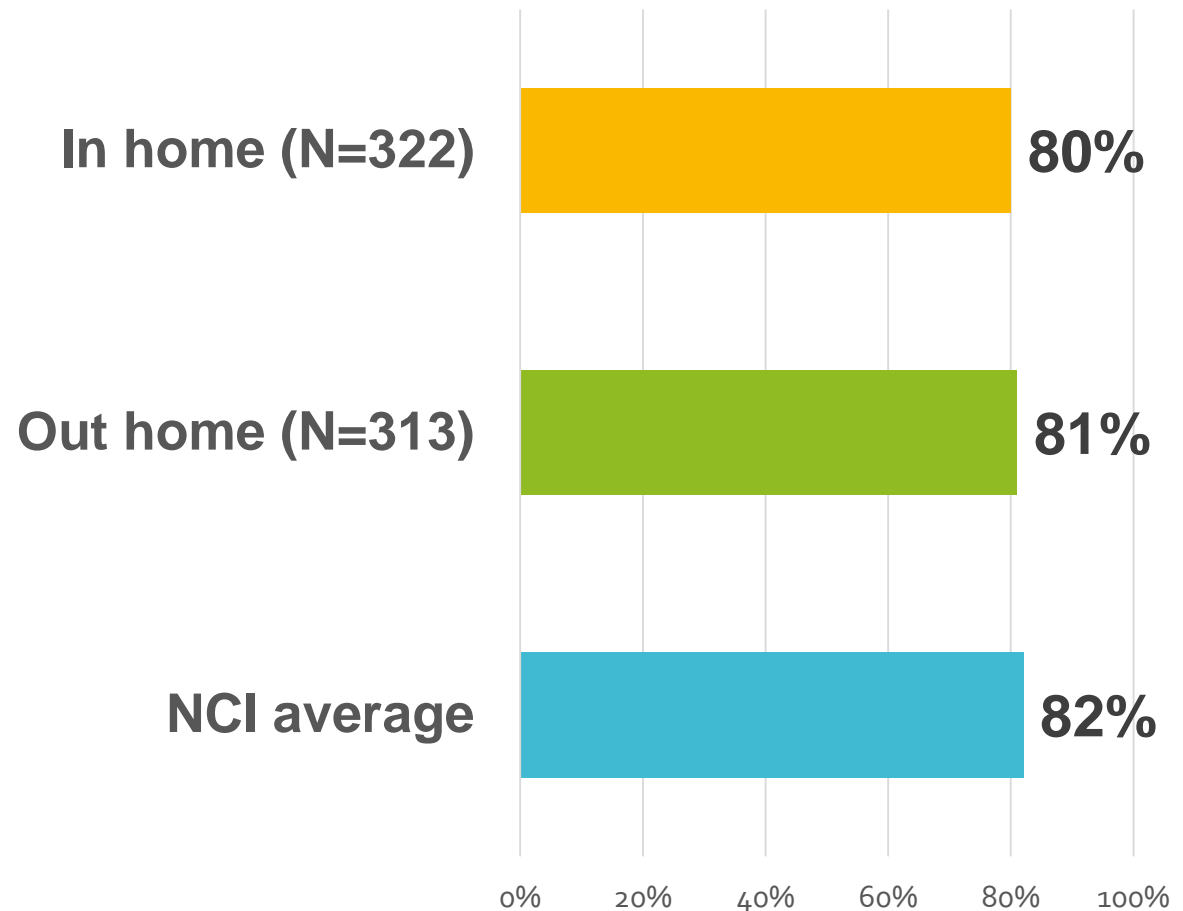
Person centered means to focus on what person wants & prefers





Service plan includes ALL NEEDED services & supports

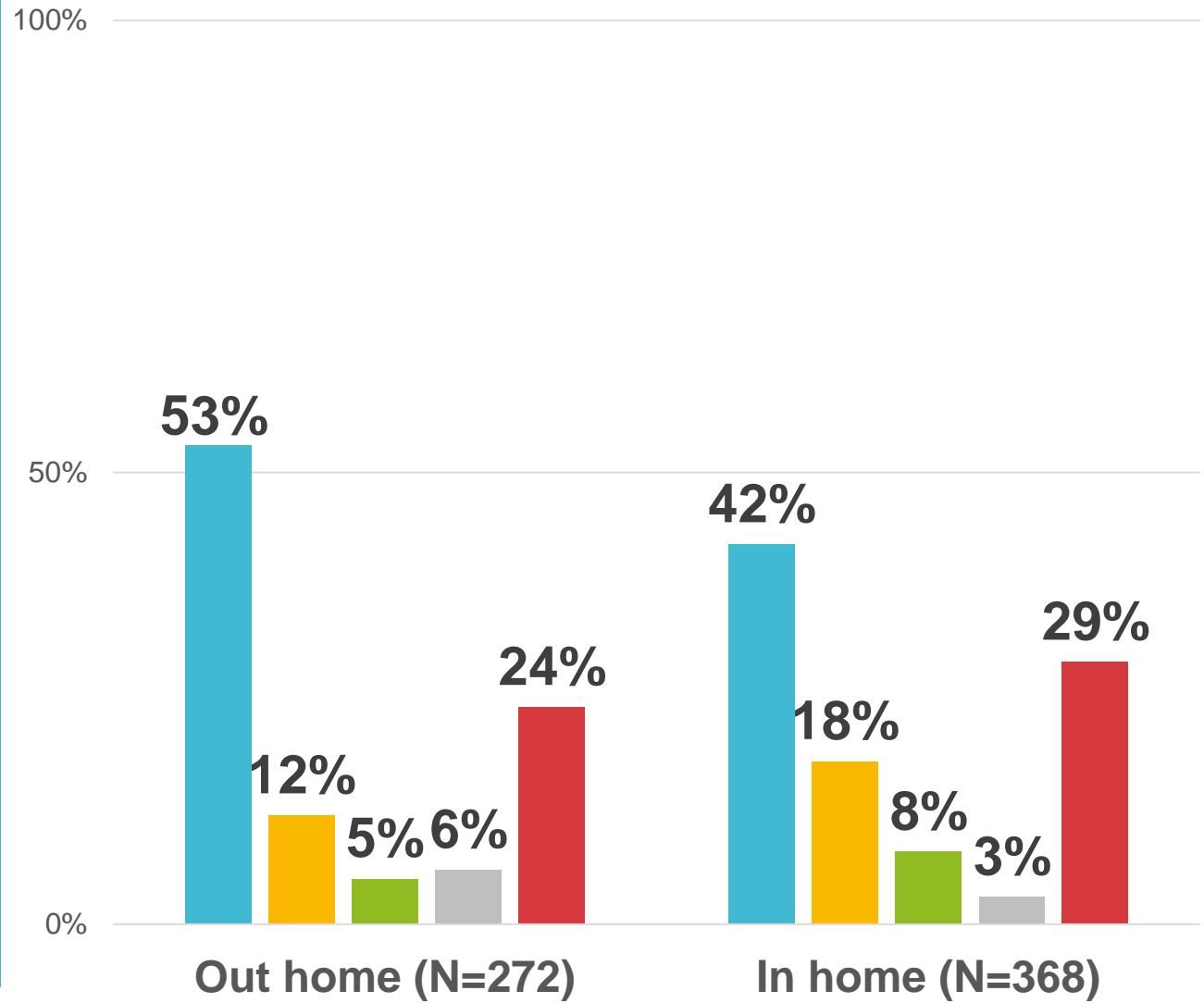
Service plan has **ALL** services & supports person receiving services **NEEDS**





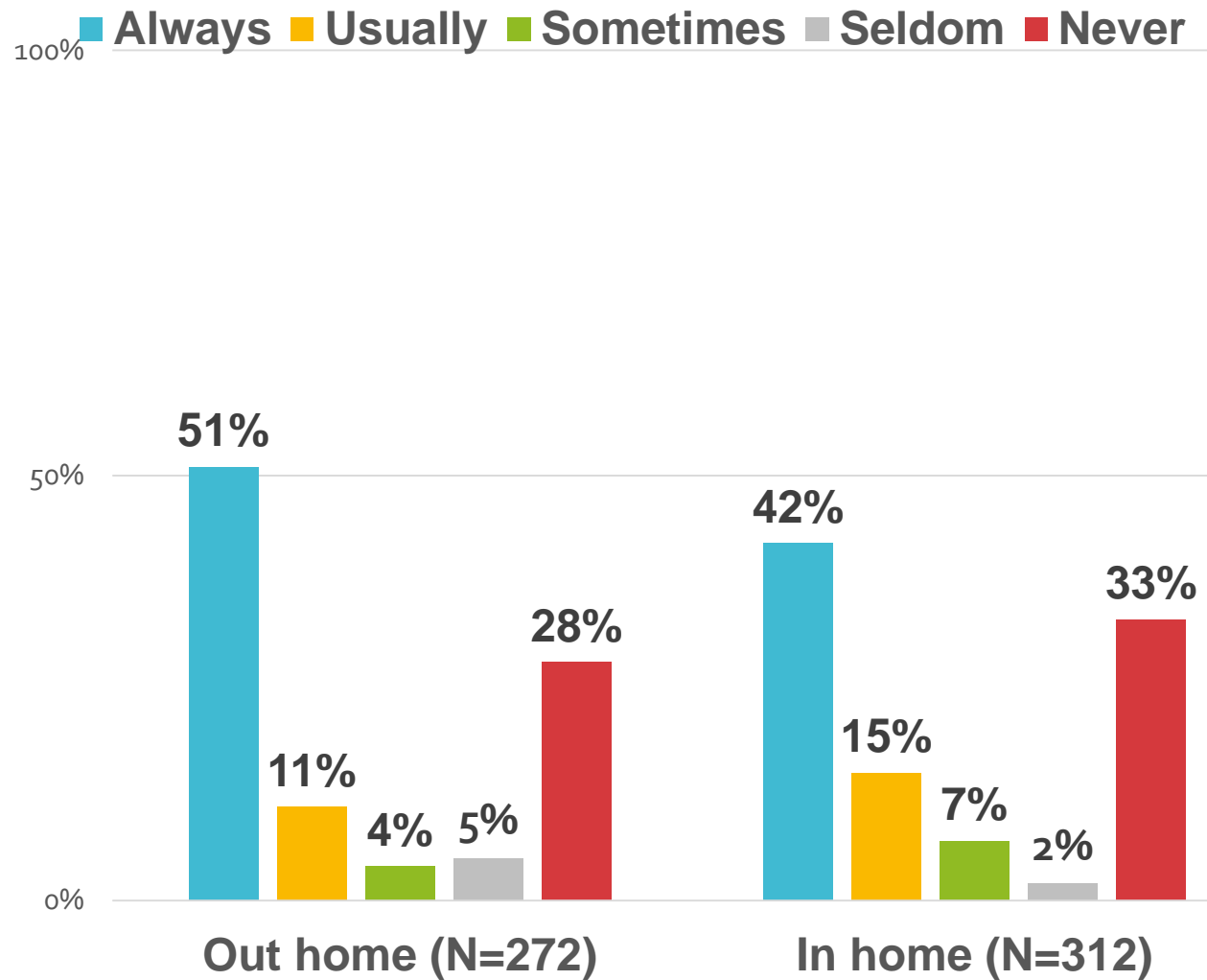
Always Usually Sometimes Seldom Never

Individual
chose
agency
service
providers



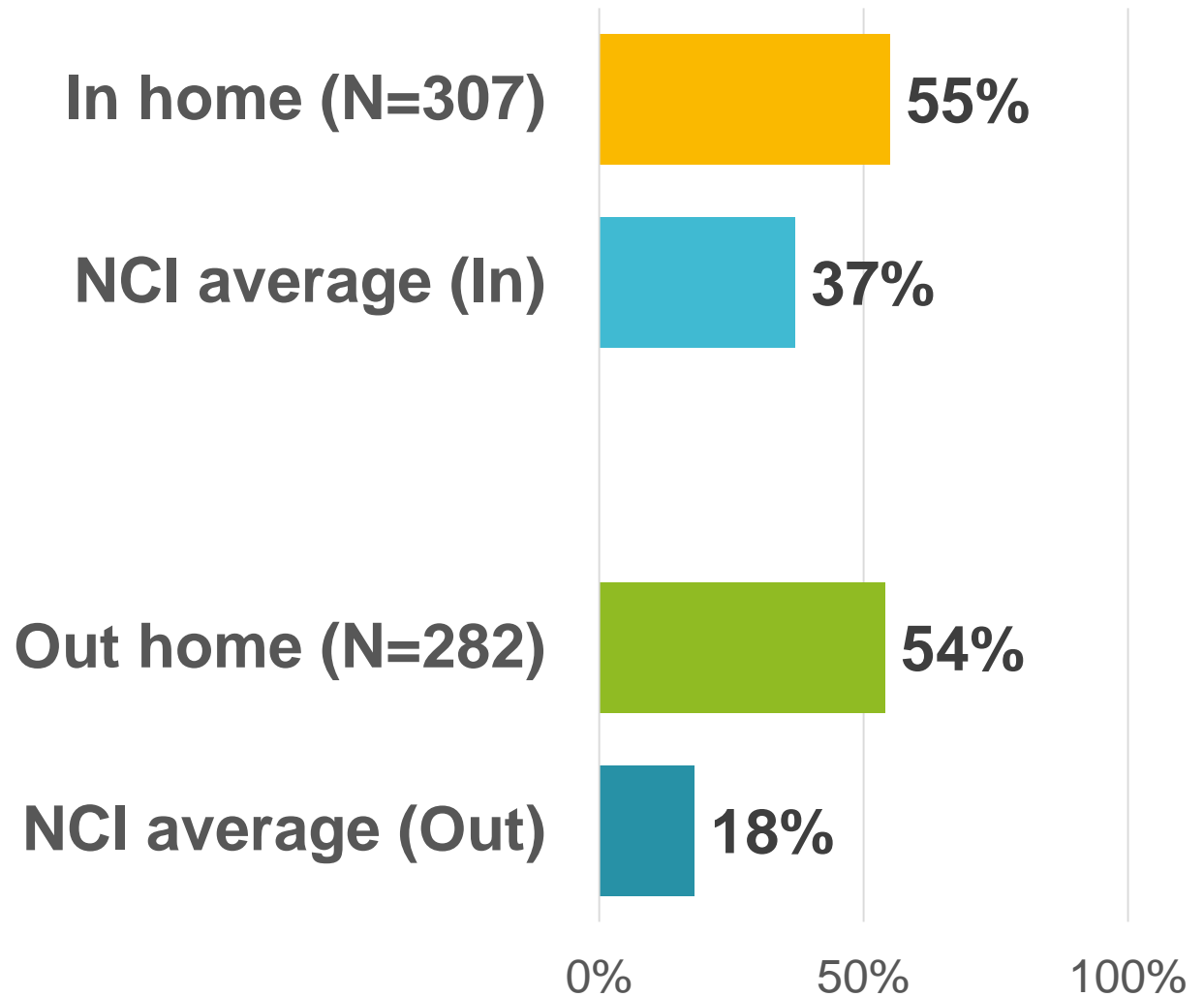


Individual
chose
support
workers
who
directly
support
him or her



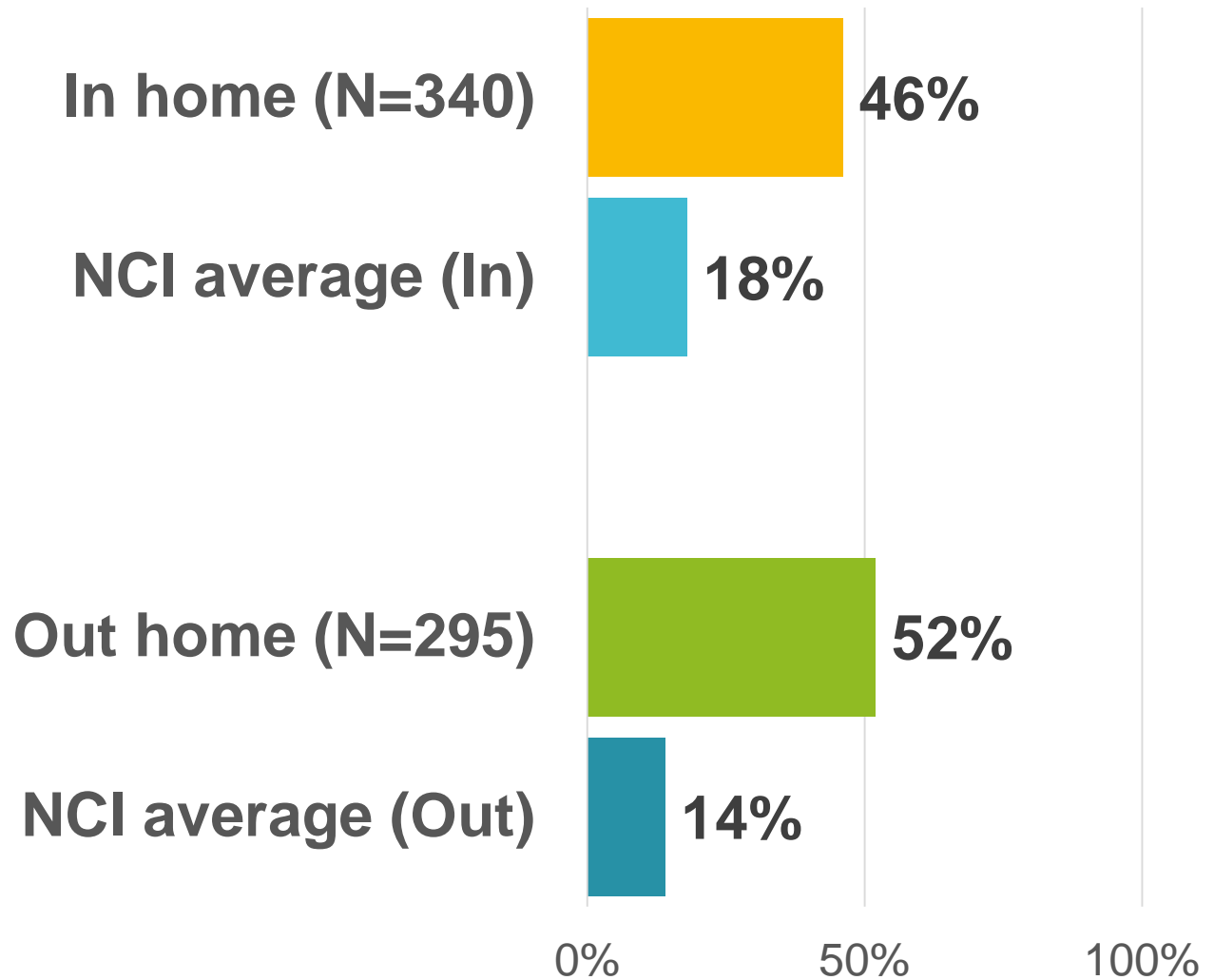


Individual has control or input over hiring & management of support workers





Individual chose Support Coordinator





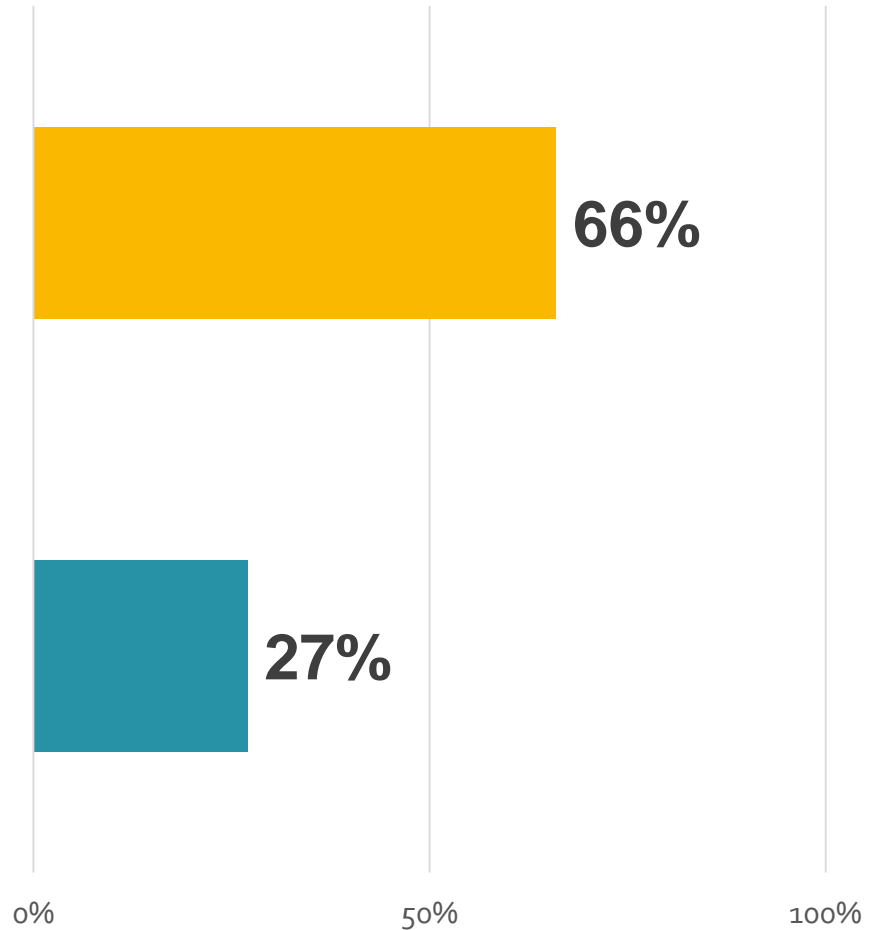
In home families chose person's Support Coordinator

In home (N=371)

66%

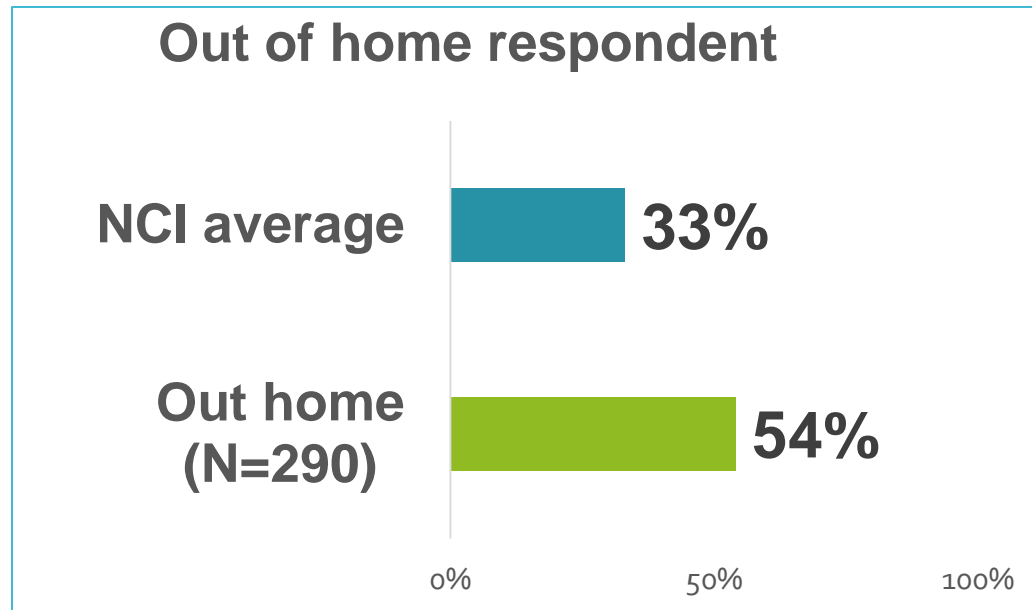
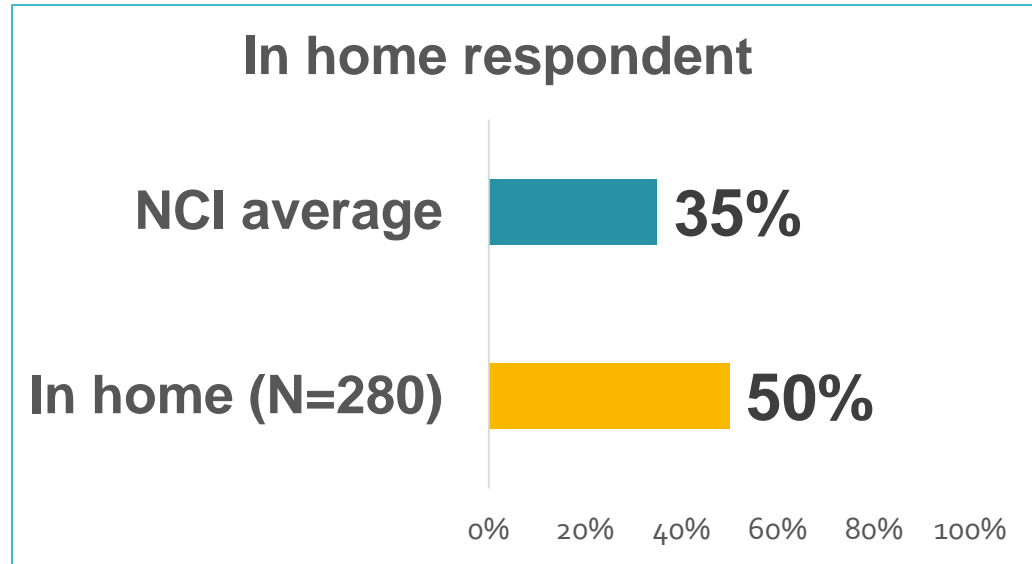
NCI average

27%





**Individual
has a say in
how I/DD
money is
spent on
his/her
behalf**



WORK & COMMUNITY LIFE

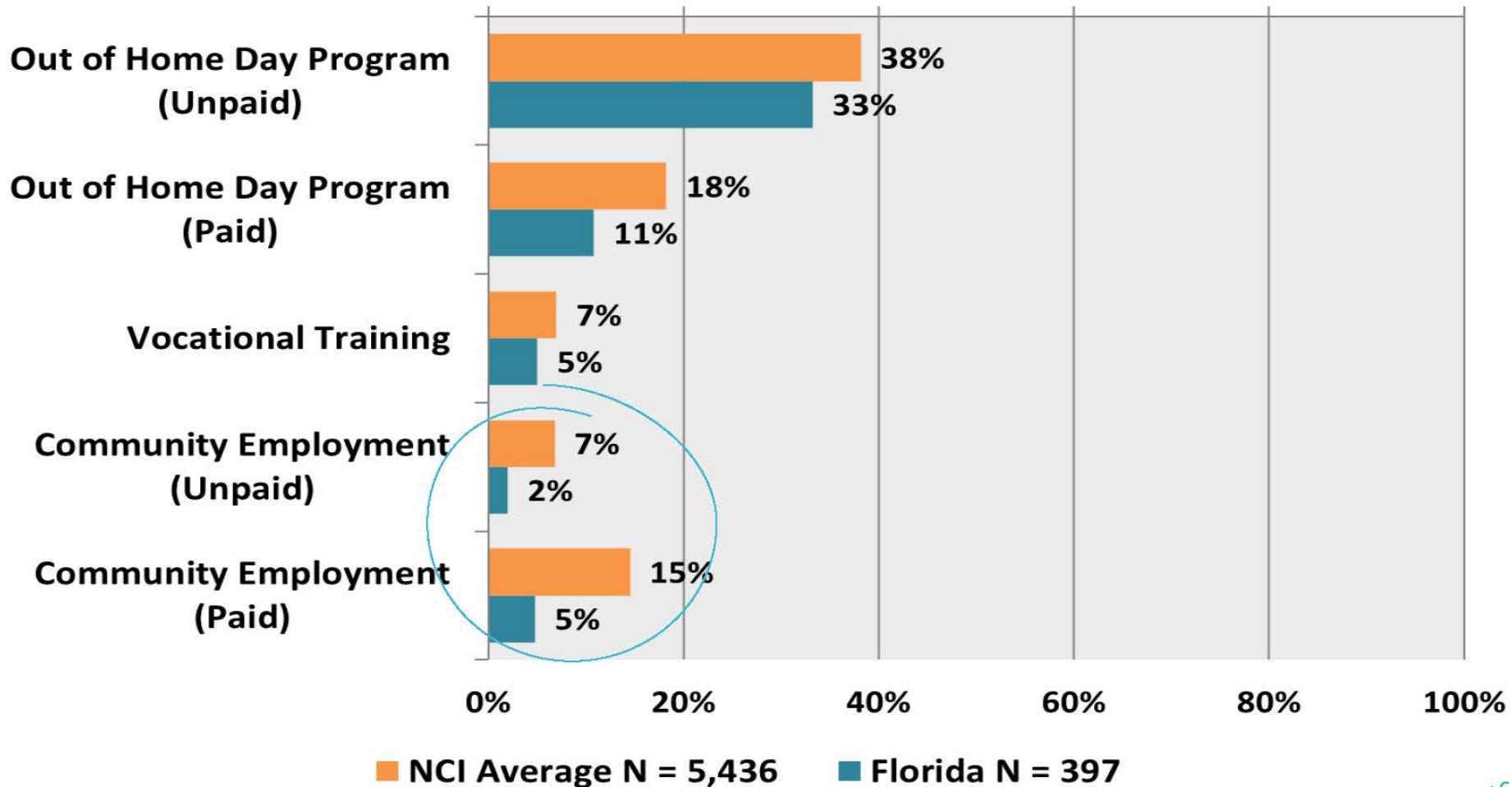
HCBS Rule requires opportunities to:

- ✓ Work in integrated settings
- ✓ Engage in community life



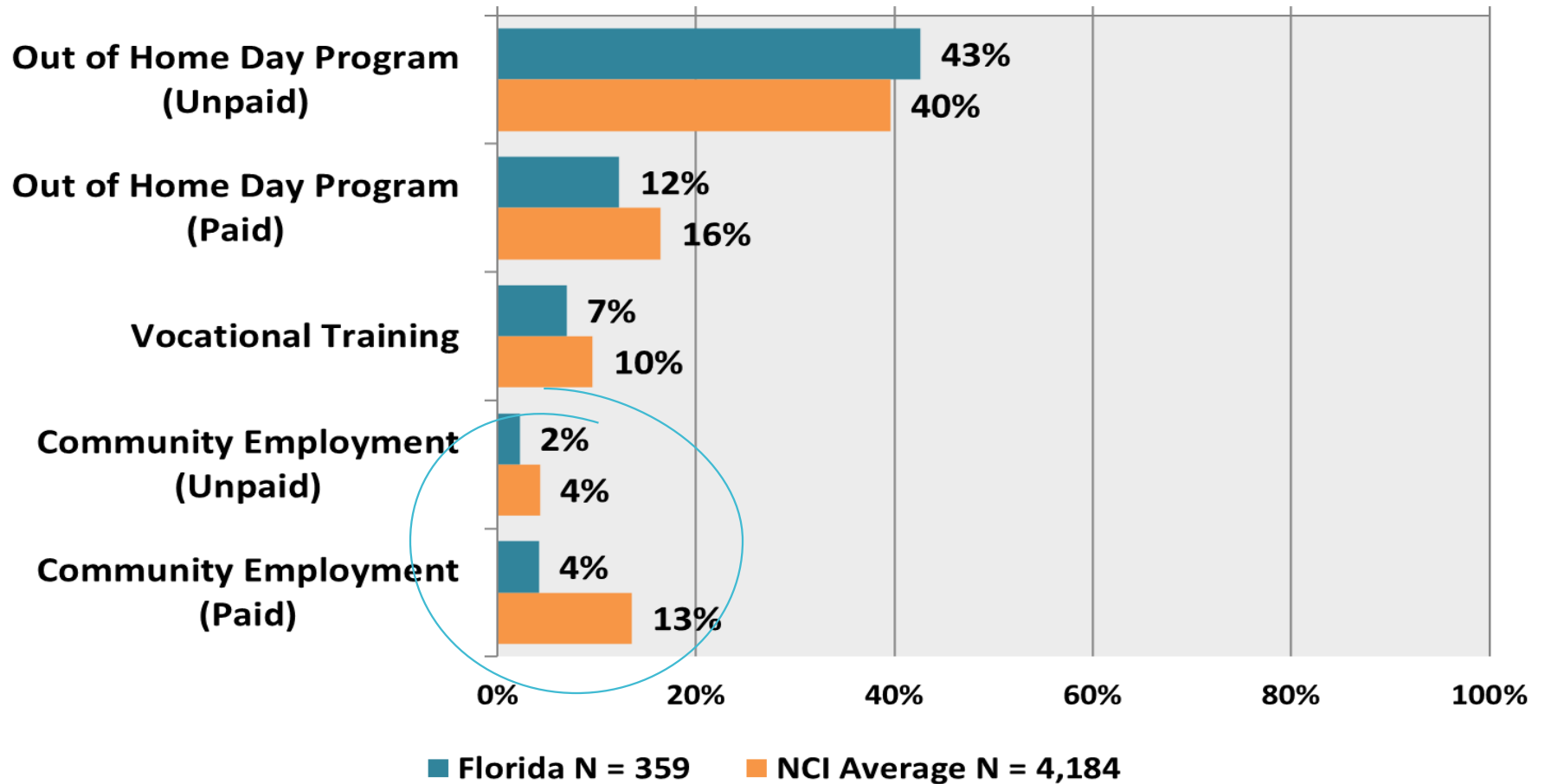
Activities of Adults Living with Family

Family Member's Typical Day Activities



Activities of Adults NOT Living with Family

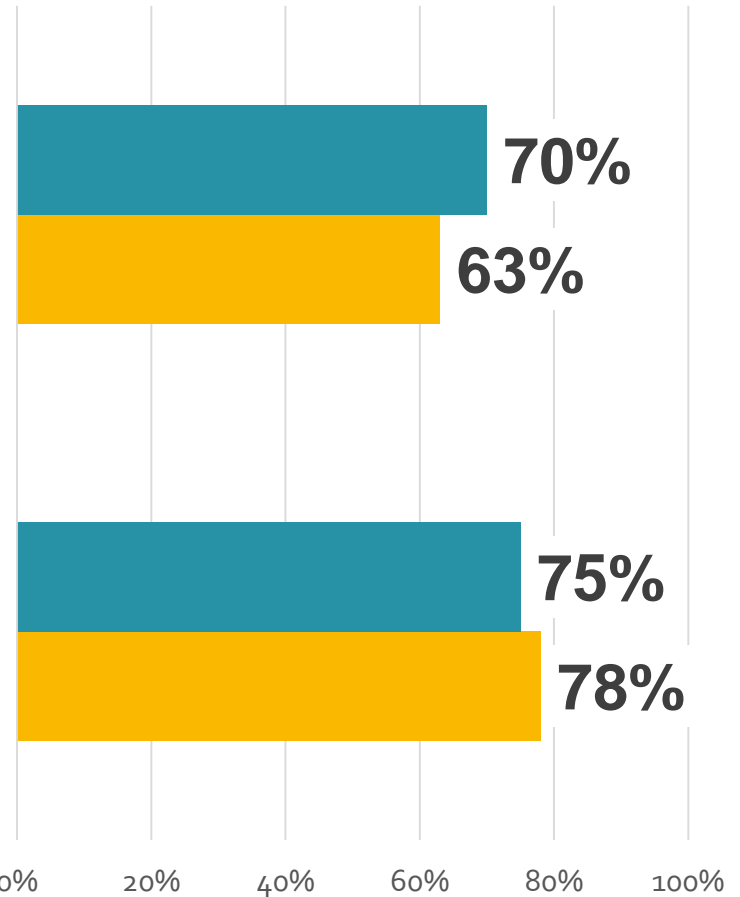
Family Member's Typical Day Activities





**Individual
has enough
support to
work or
volunteer
in the
community**

**In home family
member
(N=284)**



**Out of home
family member
(N=264)**

■ NCI Average ■ Florida

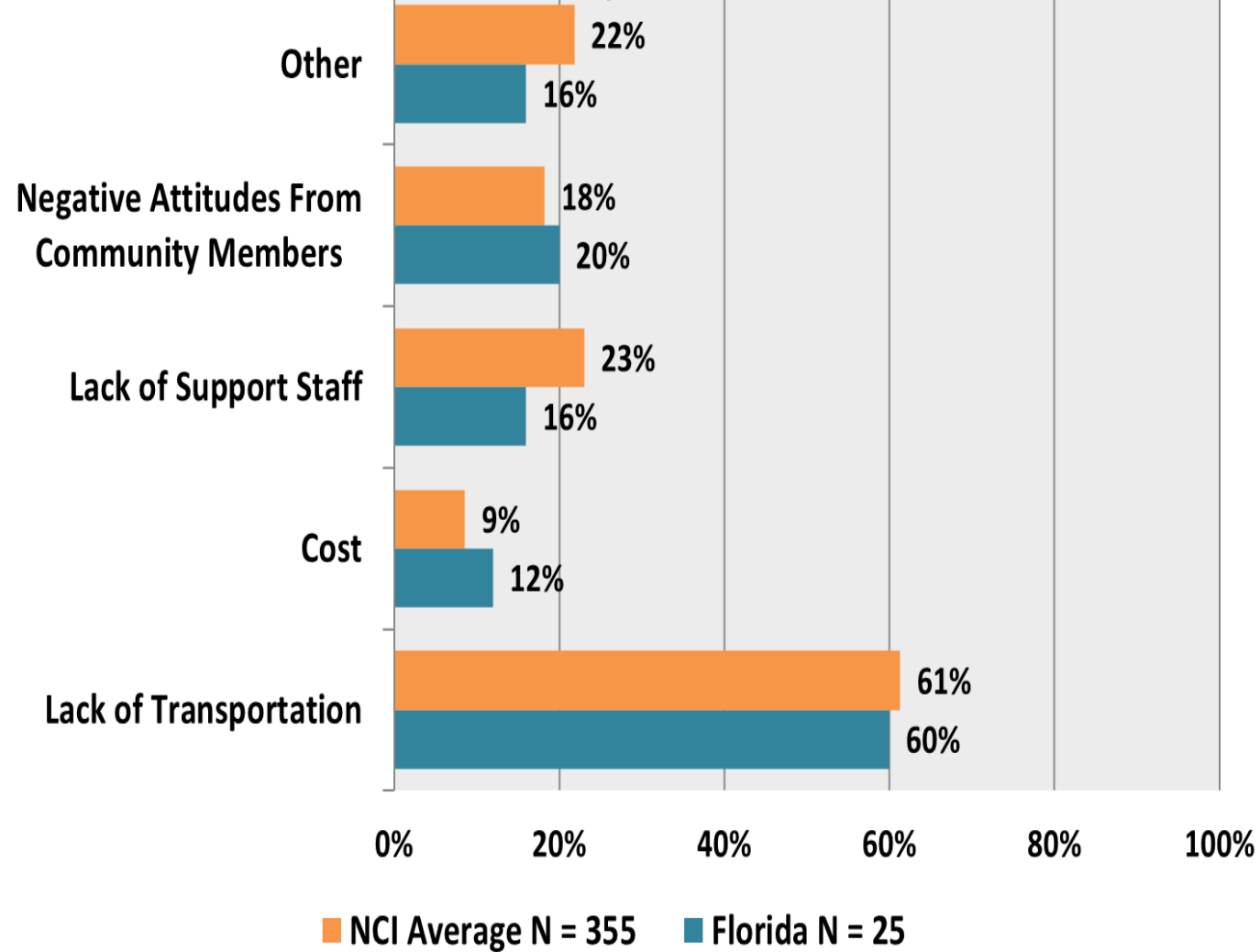
Over 90% of In & Out Home respondents reported their adult family member participates in community activities....





But for those who do NOT, In Home families explain why

Reasons Family Member Does Not Participate in Community Activities



PRIVACY & RESPECT

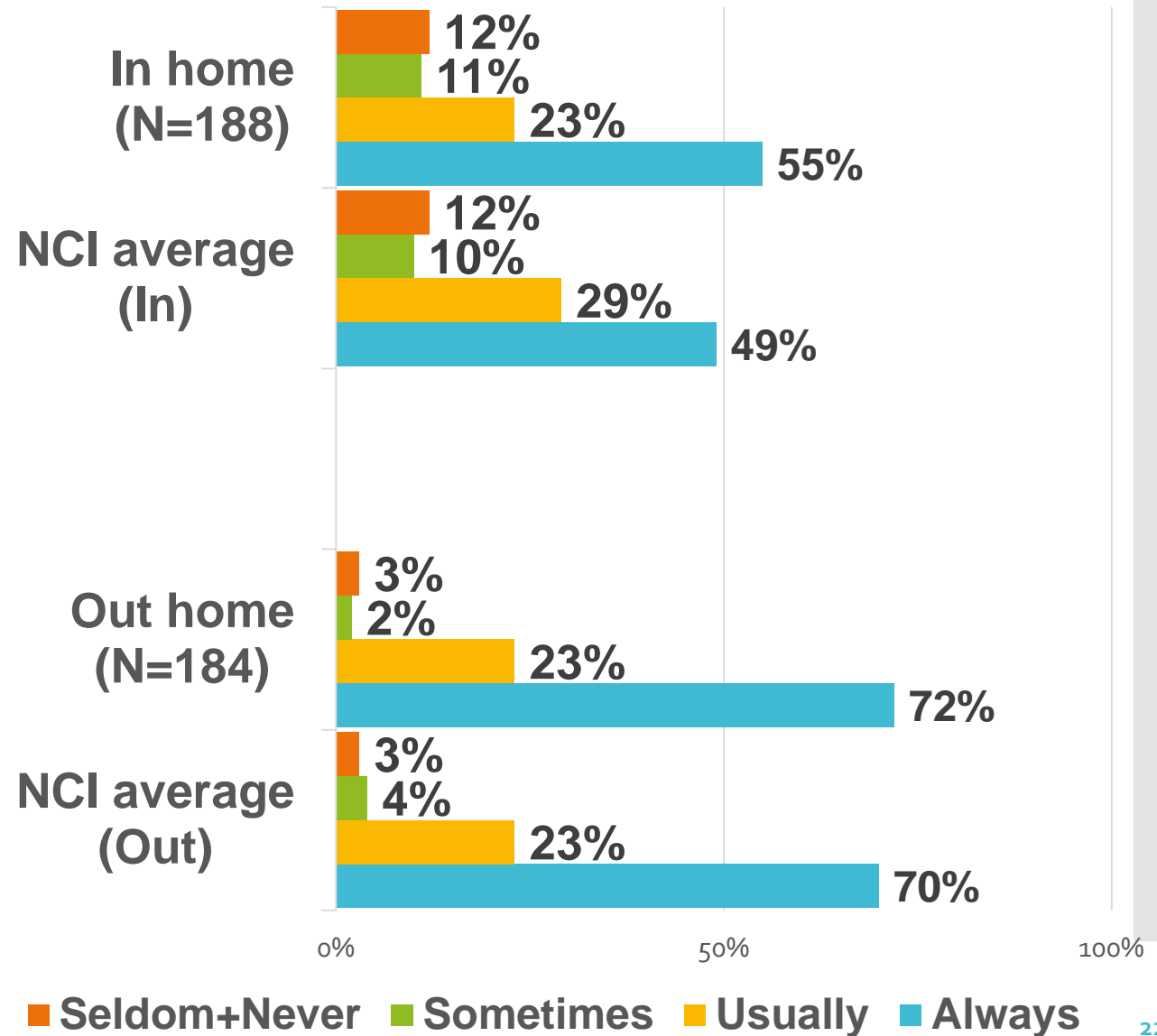
**An HCBS Setting ensures
an individual's rights of
privacy, dignity, respect,
and freedom from coercion
and restraint**





Has Equipment & Accommodations

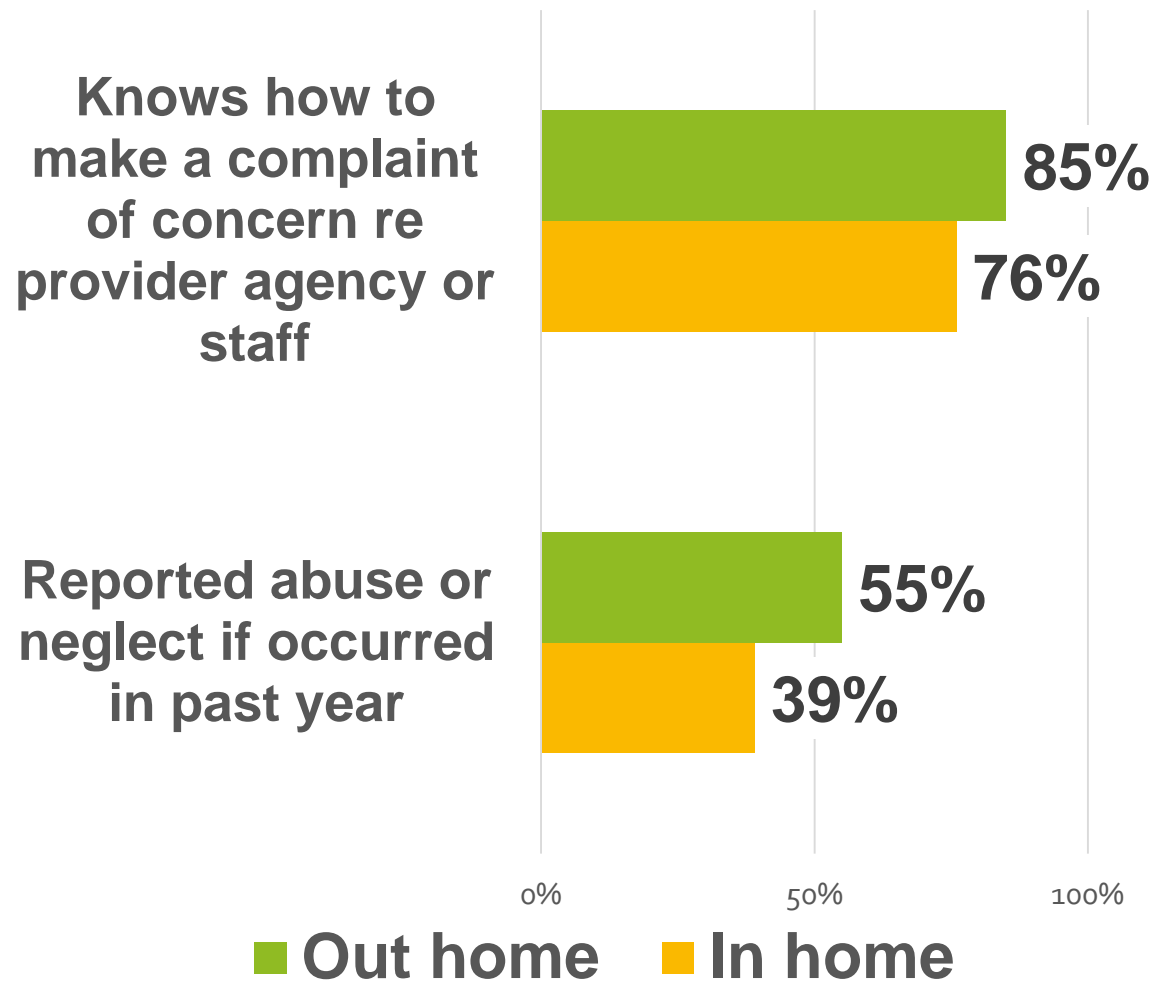
In Home –
Person has
needed
equipment or
accommodations
such as
wheelchair,
ramp,
communication
device...





Families & Guardians often do not report harm!

Reporting Harm

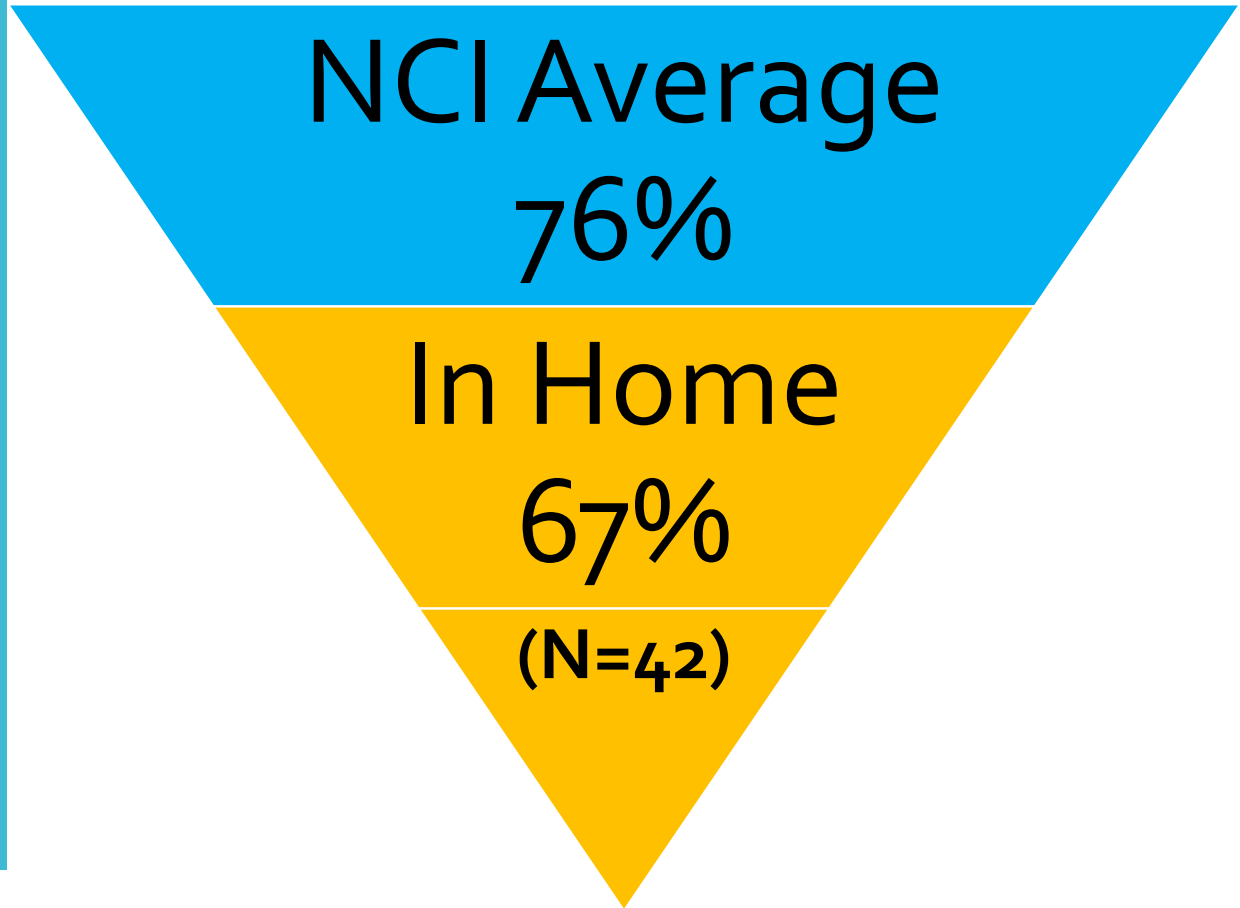


Service Impact on Families





Transition School to Adult Services: Percent "Happy" with Process

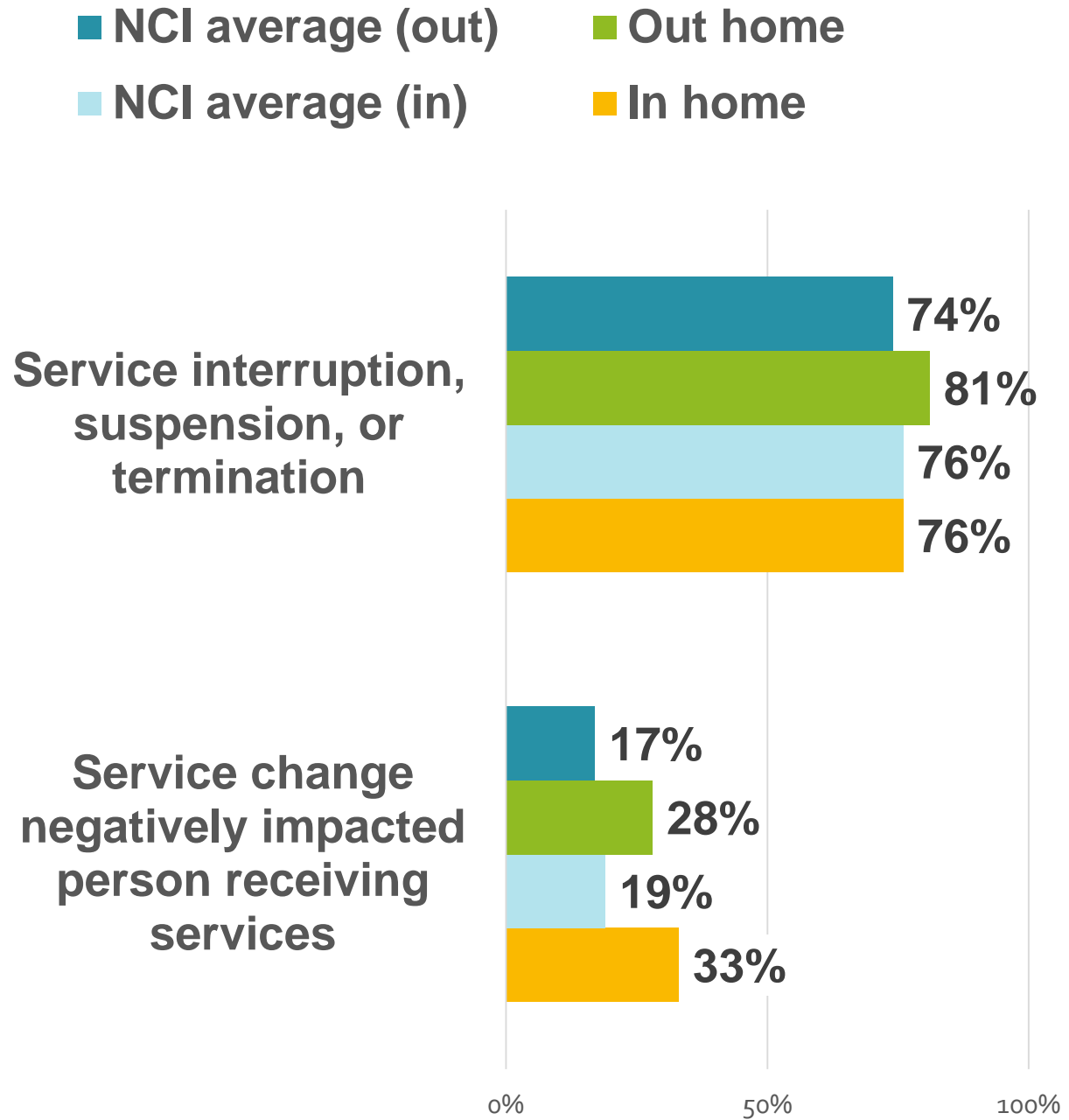


When These Services are Provided, Family Members Living with Individuals are Highly Satisfied !!!

Service Type	In Home Family Member's Access to Service	Satisfied with Service	NCI Average Access to Service
Health services	78%	94%	87%
Medication	98%	99%	99%
Mental health	88%	94%	90%
Dental	78%	94%	78%
Respite	76%	99%	78%



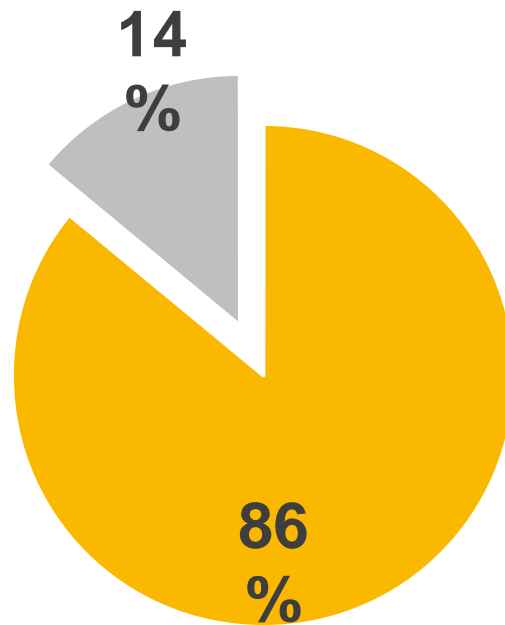
Service suspension, interruption or termination





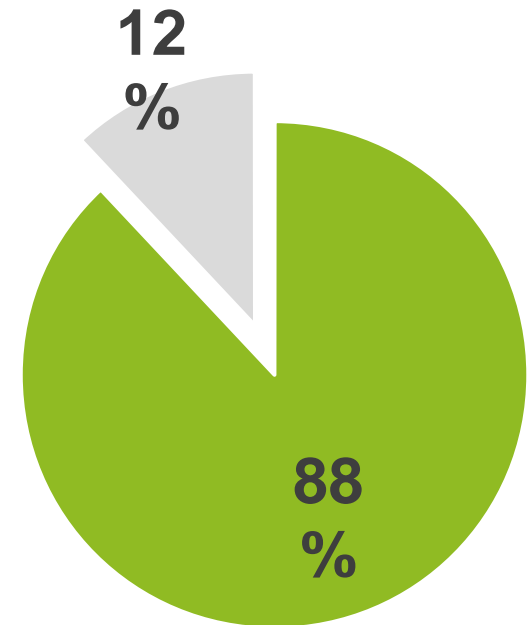
Services & supports reduced out of pocket expenses

**In Home Family Member
(N=348)**



■ Yes ■ No

**Out of Home Family Member
(N=285)**



■ Yes ■ No



Family Support initiative across states



SUPPORTING FAMILIES

of individuals with intellectual & developmental disabilities

THE NATIONAL COMMUNITY OF PRACTICE • FUNDED BY THE ADMINISTRATION ON INTELLECTUAL & DEVELOPMENTAL DISABILITIES

<http://supportstofamilies.org/cop-project-leadership-update/>

National Services Reflection



- Federal policies and recent court orders will continue to shape the service landscape – continually pushing us to more inclusive alternatives
- Self directing services is also getting more attention from federal government – requiring person-centered approaches
- What people do during the day will be a continuing issue especially as sheltered workshops and day programs transition to individualized & integrated services.
- Family support across the lifespan is evolving to reflect current philosophy and resources.

NCI Data Reflections Florida

- More adults receiving services in Florida are involved in choosing provider agencies, Support Coordinators, managing staff, & deciding how to use funds.
- Substantially fewer adults in Florida are employed in integrated settings regardless of whether they live with family or not.
- Families and guardians are not reporting abuse, neglect & exploitation. Particularly not when the individual lives in family home.



- Florida families have very high satisfaction with services received – except for Transition to adult services. But when services are interrupted or ended, families and guardians in Florida are much more negatively impacted.