

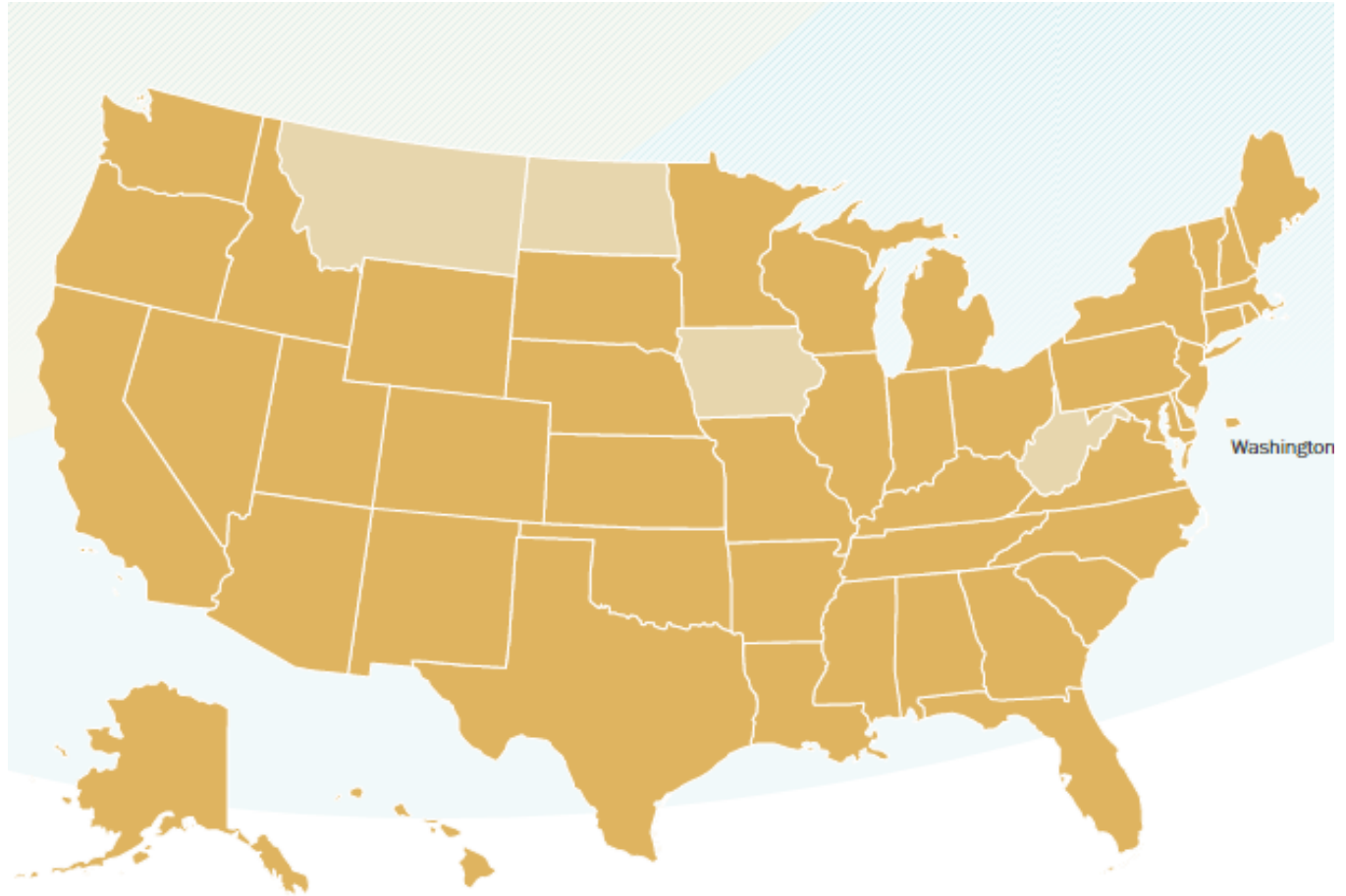
**National Core Indicators (NCI)
Data Highlights from Past Year of
Quality Council Presentations**

WHAT CALLS OUT FOR ACTION?!

Florida Statewide Quality Council Meeting
November 2016

Elizabeth Pell, Policy Associate
Human Services Research Institute
www.hsri.org :: epell@hsri.org

National Core Indicators (NCI) Member States 2016



NCI Data Focus October 2015

Rights, Valued Social Role & Outcomes

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



Experiences are Different by Legal Status

People without guardians were 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



AccessTheVote.org



Voting Education For Floridians With Disabilities



**NOT YET REGISTERED TO VOTE
CLICK HERE**

**REGISTERED VOTERS
CLICK HERE**

Florida has a new initiative to assist people with disabilities to vote. Most people receiving services even when under guardianship can vote. The right to vote for people with I/DD has to be specifically removed by a judge in Florida.

Florida Voting Requirement: ID

Bring one of the following IDs that shows your photo and signature:

- Florida driver's license
- Florida ID card
- US passport
- Debit or credit card
- Military ID
- Student ID
- Retirement center ID
- Neighborhood association ID
- Public assistance ID
- Veteran health ID card
- License to carry a concealed weapon or firearm
- Employee ID card issued by the federal government, the state of Florida, or any county or municipality

If you're a first time Florida voter who registered by mail and you didn't provide ID when you registered, you'll need to provide a photocopy of one of the following forms of ID along with your mail ballot:

- A copy of a current photo ID
- A copy of a current utility bill, bank statement, government check, paycheck, or other government document that shows your name and address

Joint AAIDD Arc Position Statement

Position excerpt:

Regardless of their guardianship status, all individuals with I/DD retain their fundamental civil and human rights (such as the right to vote and the right to make decisions related to sexual activity, marriage and divorce, birth control, and sterilization) unless the specific right is explicitly limited by court order.



2016 AAIDD adopted & Arc Board passed the Autonomy, Decision-Making Supports and Guardianship Position Statement

National Guardianship Association Revised Standards

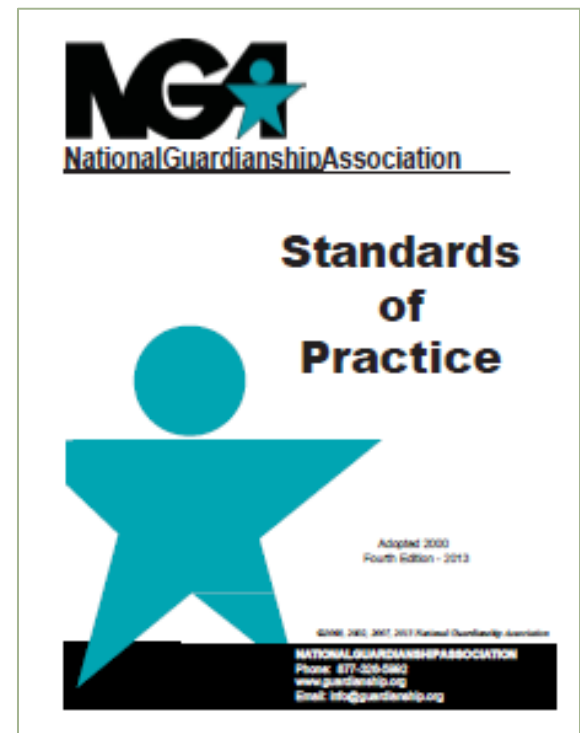
2013 changed standards to best practice. Some standards go beyond state law requirements.

Standard 7 – Standards for Decision-Making

Guardian **shall** identify and advocate for the *person's* goals, needs, and preferences.

Specifies steps, including:

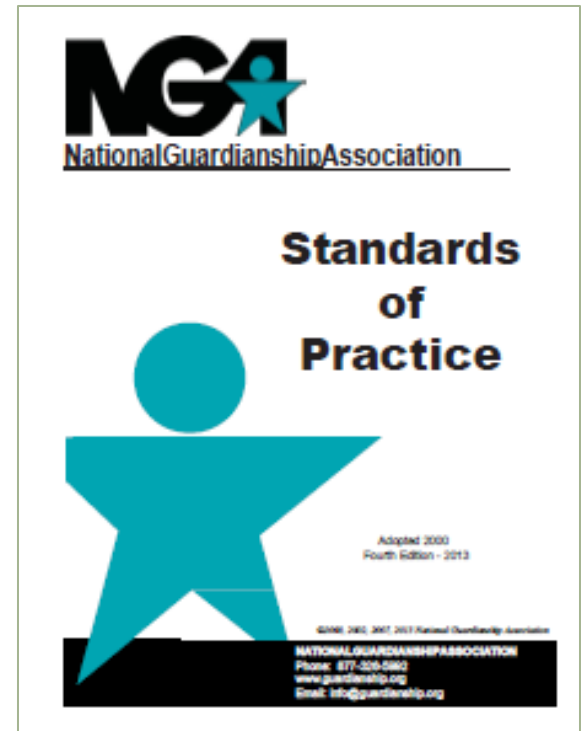
- 1st - Ask person what he or she wants
- 2nd - Do everything possible to help person express goals, needs, and preferences.
- 3rd - Only if person even with assistance is unable to convey preferences, then seek input from others who know person well to determine what person would want.



National Guardianship Association Revised Standards

Standard 9 – Self-Determination of Person

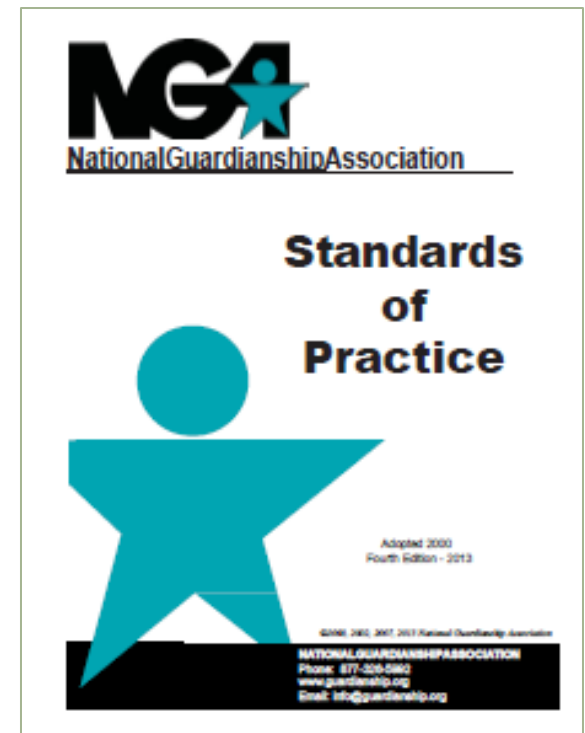
- Guardian **shall** attempt to maximize the self-reliance and independence of the person.
- Guardian **shall** encourage person to participate, ...in all decisions that affect him or her, to act on his or her own behalf in all matters in which person is able to do so, and to develop or regain his or her own capacity to maximum extent.
- **Shall** ensure the person leads planning processes; or at a minimum, participates.



National Guardianship Association Revised Standards

Standard 10 – Duties Regarding Diversity and Personal Preferences of Person

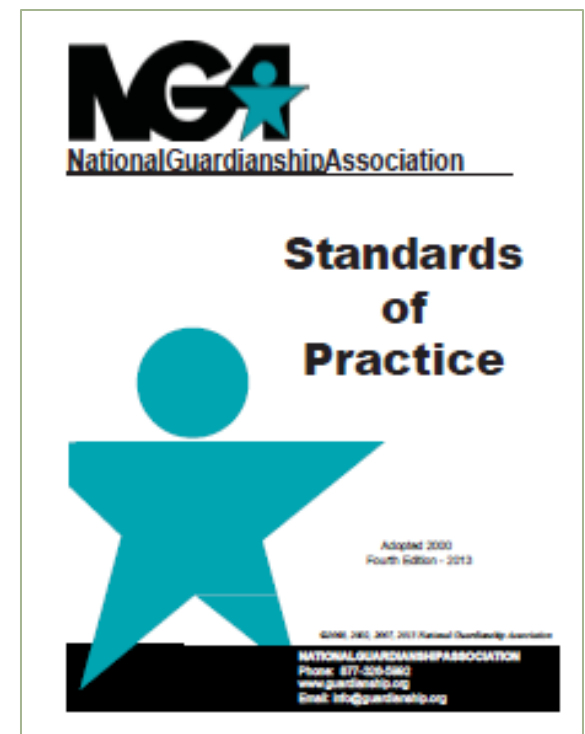
- Guardian **shall** determine extent to which person identifies with particular ethnic, cultural, religious values and apply those when considering decisions.
- Ensure person's right to consensual sexual expression, to privacy and accommodations for sexual expression, to be informed of birth control options.



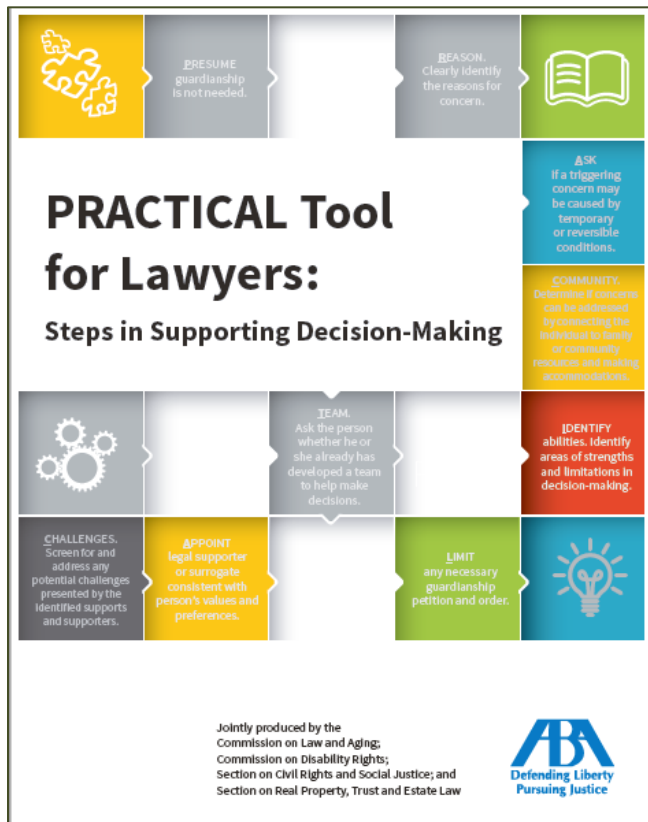
National Guardianship Association Revised Standards

Standard 12 – Termination & Limitation of Guardianship

- Guardian **shall** assist the person under guardianship to develop or regain the capacity to manage personal or financial affairs
- **Shall** seek termination or limitation of the guardianship when:
 - Person develops or regains capacity
 - Less restrictive alternatives exist
 - Person expresses the desire to challenge all or part of the guardianship....



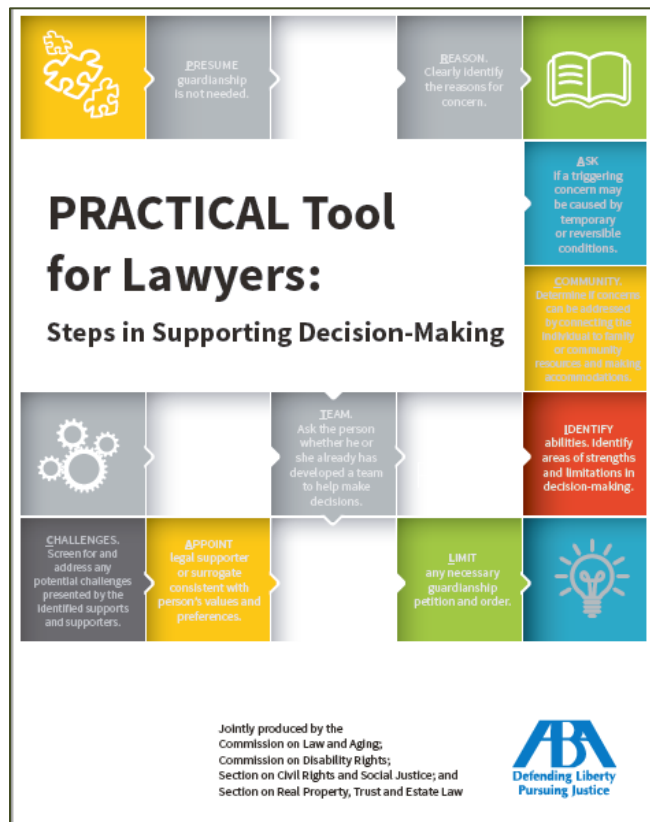
American Bar Association 2016 PRACTICAL TOOL



- **PRESUME** guardianship is not needed.
- **REASON.** Clearly identify the reasons for concern.
- **ASK** if a triggering concern may be caused by **temporary or reversible conditions.** Look for steps to reverse the condition or postpone a decision until the condition improves.
- **COMMUNITY.** Determine if concerns can be **addressed by connecting the individual to family or community resources & making accommodations.** Ask “what would it take?” to enable the person to make the needed decision(s) or address the presenting concern.
- **TEAM.** Ask the person whether he or she already has developed a team to help make decisions.

American Bar Association 2016

- **IDENTIFY** abilities. Identify areas of strengths and limitations in decision-making if the person does not have an existing team and has difficulty with specific types of decisions.
- **CHALLENGES**. Screen for and address any potential challenges presented by the identified supports and supporters.
- **APPOINT** legal supporter or surrogate consistent with person's values and preferences.
- **LIMIT** any necessary guardianship petition and order.



Available at: <http://www.ambar.org/practicaltool>

Supported Decision Making (SDM): Alternative to Guardianship

- SDM is when a person with a disability selects representatives to assist with decision-making, usually financial or health care, social life
- SDM pilots in TX, NY, NC and MA. Massachusetts pilot SDM with adults in adult foster care and shared living.
- Amanda, SDM adopter: <http://supporteddecisions.org/amanda/>
- Paige, Advisory Council member:
<http://supporteddecisions.org/pilot-project/mission-history-advisory-council/>



Quality Improvement Ideas

- Educate people and families about right to vote, even under guardianship. Assist people to exercise their right to vote.
- Get involved in Florida's Restoration of Rights initiative / start SDM pilot / promote Practical Tools / NGA practice standards
- When planning services and supports consider & educate others about alternatives to guardianship to assist in decision making, including:
 - ✓ Power of attorney
 - ✓ Supported decision making agreements
 - ✓ Health care proxy
 - ✓ Shared bank accounts

NCI Data Focus March 2016

Abuse-Neglect-Exploitation Risks & Safeguards

NCI has information on choosing where live, who live with, access to friends, friendship types, and self-advocacy connections.



Risk: Abuse-Neglect-Exploitation

High Rates of A/N/E !!

- More than 70% of people with disabilities report they have been abused
- Nearly half of victims with disabilities did not report abuse
- When therapy is provided, it is helpful. Two-thirds of victims with disabilities were not referred for therapy. (2012 Disability Abuse Project national survey and report)
- A third to half of all people killed by police in U.S. have a physical or mental disability. (Ruderman Family Foundation Report 2016)

Risk Increases When...

Power or control over an individual:

- Financial authority
- Decision making authority

Socially isolated:

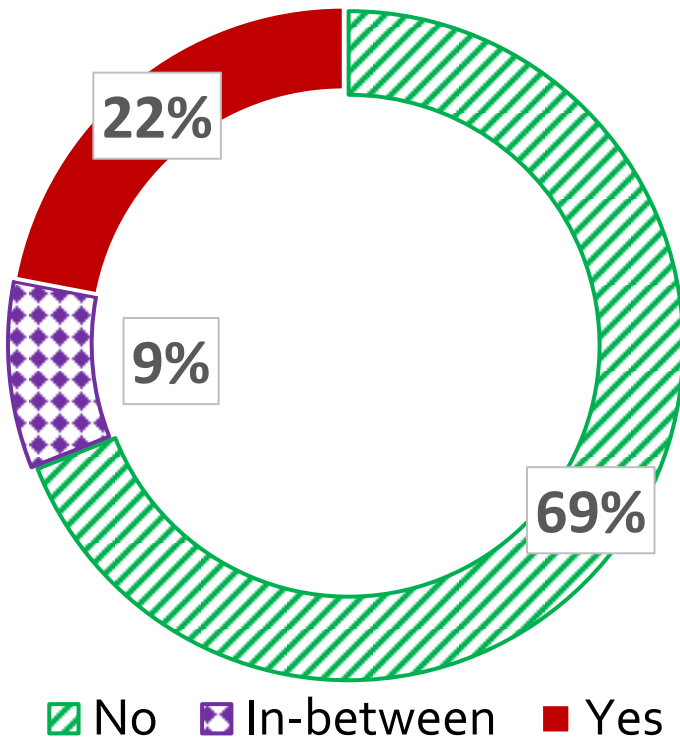
- Lacks friends & friends with general community members
- Not engaged in integrated activities, work, school

Vulnerability increases when:

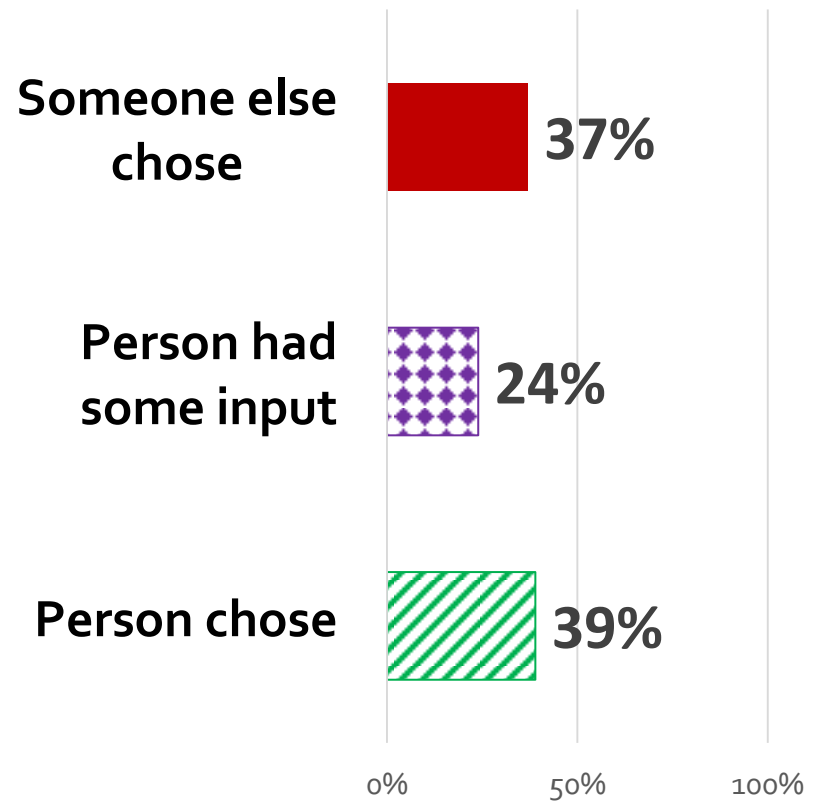
- Communication or mobility limitation
- Mental health condition or considered a behavior challenge
- Dependent for personal care

Safeguard: Choosing Where to Live

Would you like to live somewhere else? N=871

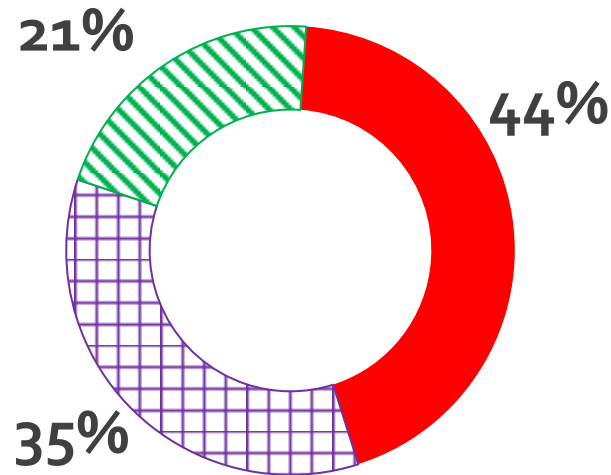


Who chose where you live? N=573



Safeguard: Choice of staff

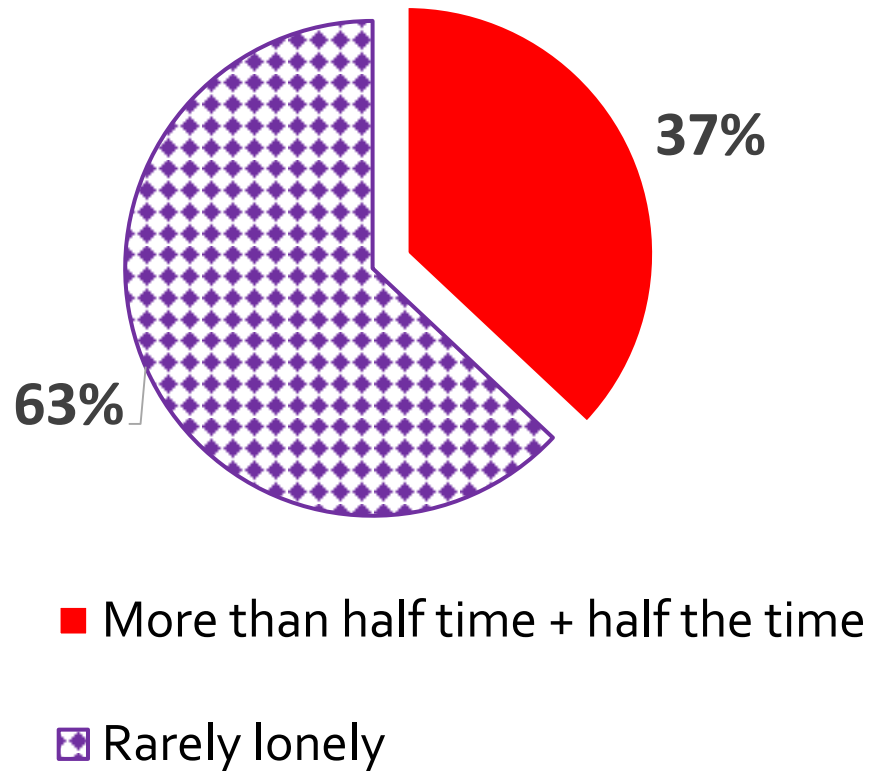
Do you chose your staff? N=1277



- Someone else chose
- ▣ Someone else chose but can request change
- ▤ Person chose

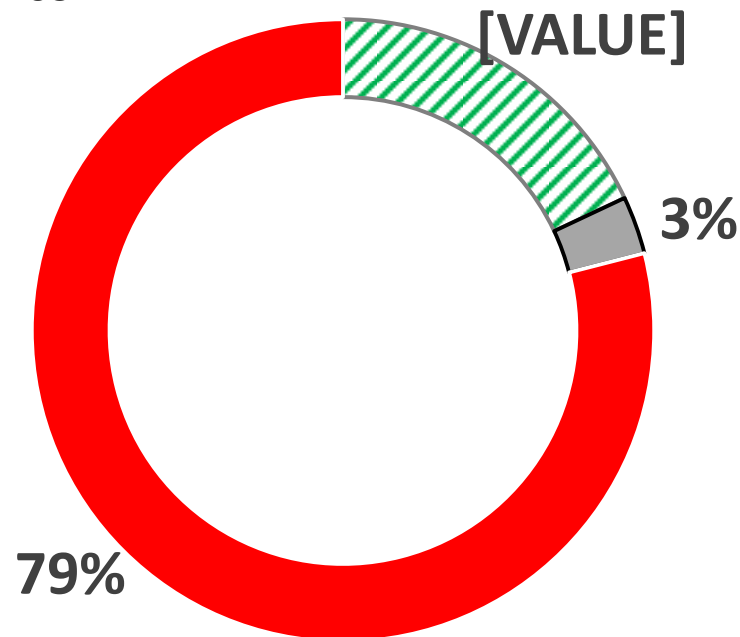
Safeguard: Social Connections

Do you ever feel lonely? N=842



Safeguard: Self Advocacy

Have you ever participated in a self advocacy meeting or event? N=1209



 Yes  Had opportunity  No

Source: Florida's NCI Adult Consumer Survey 2014-15

Quality Improvement Ideas

- Recommend improvements to abuse registry & background checks to keep known perpetrators from working
- Offer policy recommendations regarding state agencies timely sharing of investigation findings.
- Recommend standard practice to offer victim's services offered to general population in the criminal justice system to those with I/DD
- Recommend standard practice to offer trauma-competent therapy or counseling for victims of abuse, neglect, exploitation
- Recommend standard practice to ask people about their experiences, about abuse, prior to service planning meetings. Individualize risk reduction as part of service planning.

Quality Improvement Ideas

- Help people with I/DD have more relationships with community members. Start a local or statewide *Friends* resource users. Hold monthly progress and problem solving meetings (phone/in person).
- Create more self advocacy organizations across state
- Ensure adults receiving services are periodically offered choices of where to live and staff providing them services
- Recommend policy that provider agencies include individuals receiving services be involved in hiring staff
- Recommend policy that providers include feedback from individuals in each staff person's performance evaluation.

NCI Data Focus July 2016

Family & Guardian Surveys

NCI mail surveys are sent to 2 groups:

- Family members living with an adult receiving services (“in home”)
- Family members or guardians that do not live with adult receiving services (“out of home”)

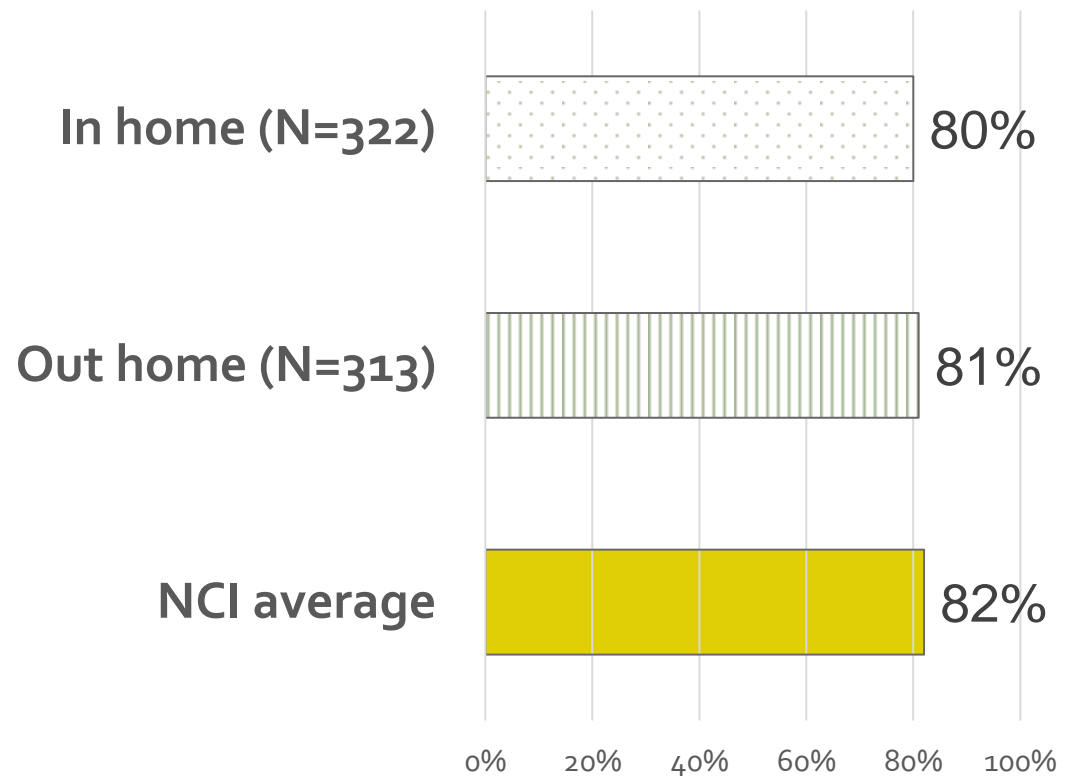


Family & Guardian Mail Surveys 2014-15 Recap

- Many adults are not receiving all the services and supports needed.
- Though more adults receiving services in Florida are involved in choosing provider agencies, Support Coordinators, & deciding how to use funds, many are not making these choices.
- 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.

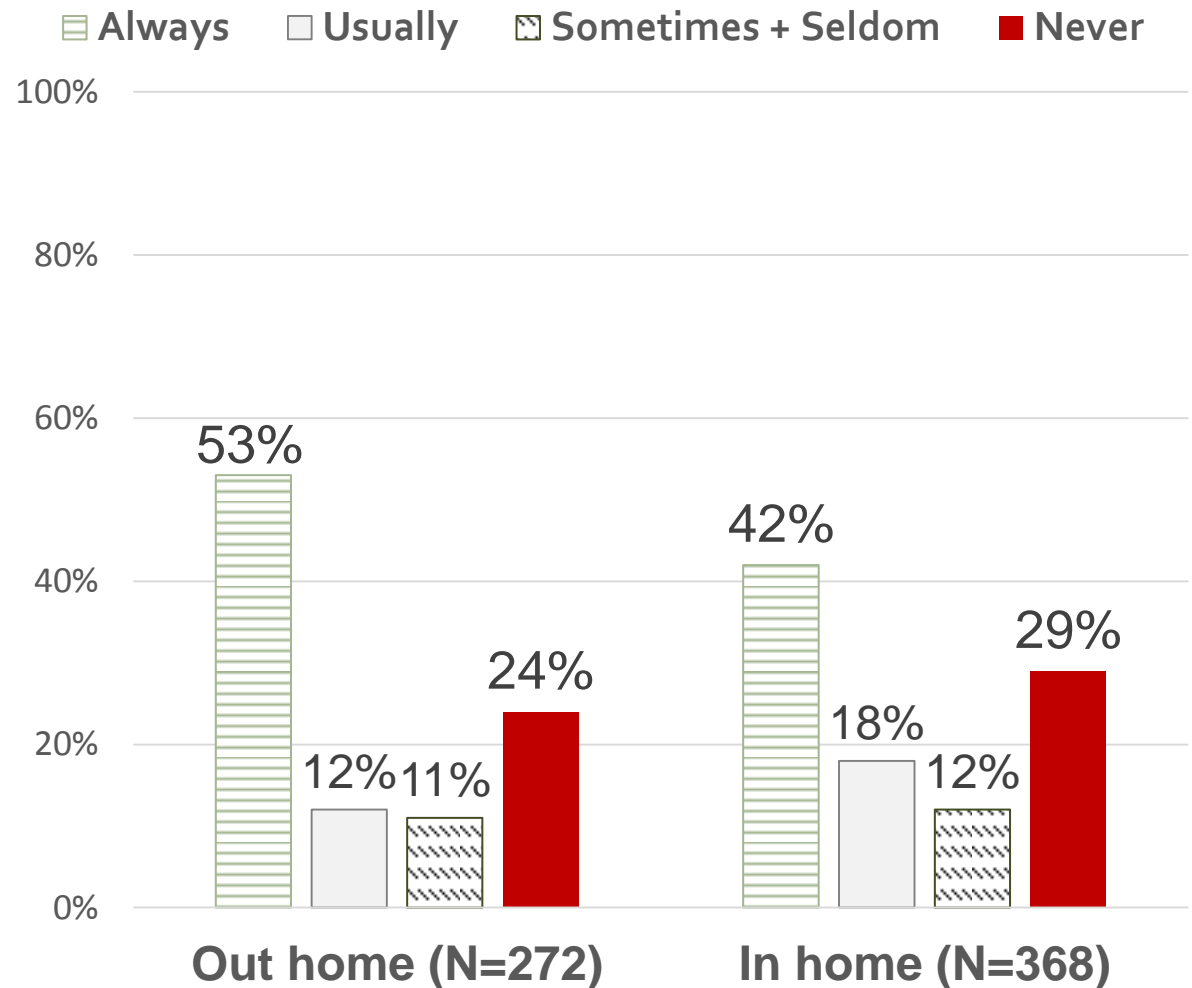
Support Plan Has ALL Services & Supports Person Receiving Services NEEDS

According to families & guardians, 1 of every 5 adults receiving services is not receiving all services & supports needed.



Individual Chose Agency Service Providers

Approximately
1 in 4
individuals has
never had
choice of their
service provider
agencies.





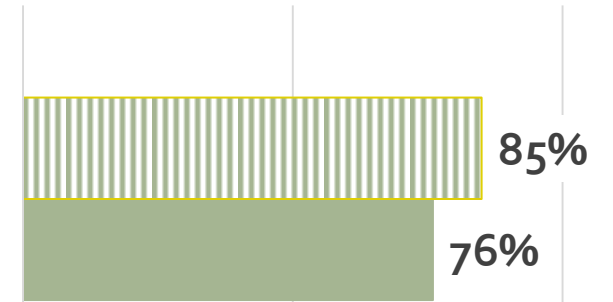
Integrated Paid Work

Adult Consumer Survey	Adult Consumer Survey	In Home Family Survey	Out of Home Family Survey
17% NCI Average	9% Florida	5% N=397	4% N=397

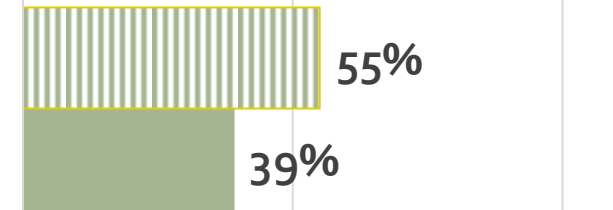
Risk: Families & Guardians Often Do Not Report Harm



Knows how to make a complaint of concern re provider agency or staff



Reported abuse or neglect if occurred in past year



Out home In home

Quality Improvement Ideas

Choice-making

- Recommend strategies to increase individuals' choice of service providers -- at least annually as part of service planning

Work

- Recommend rule or policy changes to streamline employment searches

Abuse/Neglect/Exploitation Reporting

- Find out why family members & guardians are not reporting suspected a/n/e. Recommend changes to increase reporting.

NCI Staff Stability Survey Launched

- Survey collects data on Direct Support Professional (DSP) turnover and vacancy rates among providers.
- 2014-15 report: Of the DSPs who left employment at responding agencies between January 1, 2014 and December 31, 2014, 37% had been employed for less than 6 months. Varied vastly by state.
- Across respondent agencies, DSP turnover rate was 45%.
- Of agencies that differentiate between full- and part-time employees, full-time vacancy rate was 7%, and 13% for part-time positions.
- DSPs received an average hourly wage of \$11.11. DSPs providing in-home and residential supports earned less on average than those providing non-residential supports.

New NCI National Reports

User-Friendly Reports

- User Friendly Adult Consumer Survey State Reports. Florida's report link: http://www.nationalcoreindicators.org/upload/core-indicators/Florida_Report_1.pdf
- User-Friendly Adult Family Survey Reports. Florida's report link: http://www.nationalcoreindicators.org/upload/core-indicators/Florida_User_Friendly_AFS_Report.pdf
- User-Friendly Family/Guardian Survey Reports. Florida's report link: http://www.nationalcoreindicators.org/upload/core-indicators/Florida_User_Friendly_FGS_Report.pdf

Topic Reports - Friendships



National Core Indicators™ DATA BRIEF

SEPTEMBER 2016 | FRIENDSHIP



What Do NCI Data Show About Friendship and Life Outcomes for Adults With Intellectual and Developmental Disabilities?

By Stephanie Giordano, Dorothy Hiersteiner, and Elizabeth Pell

Overview

Friendships enrich the lives of people with intellectual and developmental disabilities (I/DD) just as they enrich the lives of people without disabilities. Research has shown that friendships have a positive impact on health, habits and well-being, and contribute to overall quality of life.¹ However, studies have shown that people with I/DD often live with few social connections and friendships outside those with family and staff.²

For adults with I/DD, National Core Indicators™ (NCI™) data show significant differences in many areas of life, between those whose friendships are limited to family or paid staff and those with more extensive friendship networks that include other people with disabilities and people in the general population.

This NCI data brief examines those differences and identifies some resources for supporting people with I/DD to develop their relationship networks.

Create your own NCI data slides!

The image is a screenshot of the National Core Indicators (NCI) website. At the top right, there is a "STATE LOGIN" button with a dropdown arrow. The main navigation bar includes links for HOME, ABOUT, NCI STATES, CHARTS, INDICATORS, RESOURCES, BLOG, NEWS, and CONTACT. The page features a section titled "National Core Indicators™" with a descriptive paragraph and a link to "core indicators". Below this is a "Featured Core Indicators" section with three cards. Each card contains a bar chart, a title, a description, and a "READ MORE" button. The first card is "Feels Lonely", the second is "Person has Paid Job in the Community", and the third is "Allowed to Use Phone or Internet at Any Time".

NCI™

STATE LOGIN

HOME ABOUT NCI STATES CHARTS INDICATORS RESOURCES BLOG NEWS CONTACT

National Core Indicators™

National Core Indicators (NCI)™ is a voluntary effort by public developmental disabilities agencies to measure and track their own performance.

The [core indicators](#) are standard measures used across states to assess the outcomes of services provided to individuals and families. Indicators address key areas of concern including employment, rights, service planning, community inclusion, choice, and health and safety.

NCI™ is a collaboration of [participating states](#), [HSRI](#), and [NASDDDS](#).

Featured Core Indicators

Feels Lonely

The proportion of people who feel lonely

READ MORE

Person has Paid Job in the Community

The proportion of people who have a job in the community

READ MORE

Allowed to Use Phone or Internet at Any Time


The proportion of people whose basic rights are respected by others

READ MORE

<http://www.nationalcoreindicators.org/charts/>

NCI Charts

Learn how to use the NCI Chart Generator

WATCH VIDEO 


1. Measure

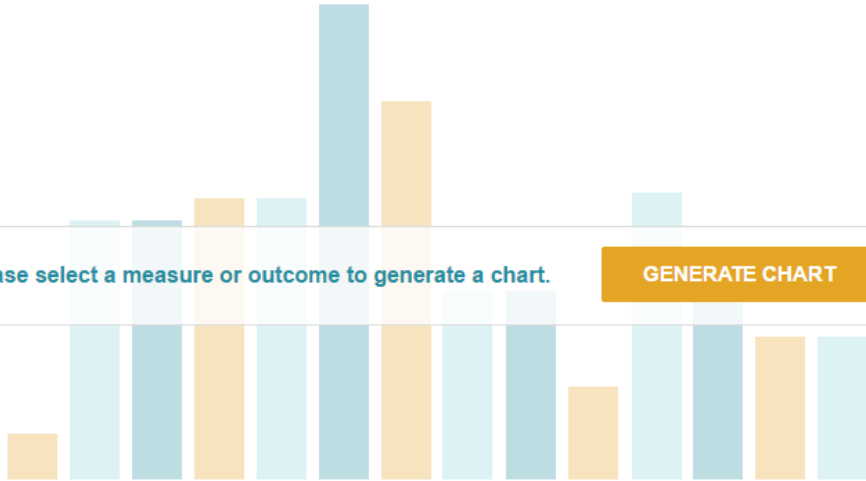
✓ *Measure or Outcome* ▼

2. Year(s)

✓ 2014-15
<input type="checkbox"/> 2013-14
<input type="checkbox"/> 2012-13
<input type="checkbox"/> 2011-12
<input type="checkbox"/> 2010-11
<input type="checkbox"/> 2009-10
<input type="checkbox"/> 2008-09

Please select a measure or outcome to generate a chart.

GENERATE CHART 



Category	Value (approx.)
1	10
2	25
3	25
4	30
5	25
6	55
7	45
8	25
9	10
10	25
11	25
12	25

WHAT NEXT FOR FLORIDA'S STATEWIDE QUALITY COUNCIL?

