What NCI Tells Us About the Aspirations of the HCBS Rule

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November 10, 2016
Overview

Quick review of the rule

Background of National Core Indicators (NCI)

NCI data related to aspirations of the HCBS rule

Constraints to achieving the desired outcomes
  ◦ Obstacles raised by providers
  ◦ Restrictions of guardianship
New HCBS Rule

WHAT DOES IT PROMISE?
Antecedents for New Rule

Normalization and the assumption that people with disabilities have the same rights to live normal lives in their communities as individuals without disabilities

Landmark court decisions including the Olmstead case that required that individuals with ID/D be supported in the community

Wide variations in the size, quality and inclusiveness of community services
New Requirements for Federally Supported Community Services

Purpose: Ensure people receiving federal funding for long-term services have full access to the benefits of community living and opportunities to receive services in the most integrated setting appropriate.

The Rule Requires that Services and Supports:

Are integrated in and support full access to greater community

Ensure the individual receives services in the community with the same degree of access as individuals not receiving federal Medicaid funding

Provide opportunities to seek employment and work in competitive integrated settings, engage in community life, and control personal resources
Supports --

Are chosen by the individual from among residential and day options that include *generic* settings.

Respect the participant’s option to choose a private unit in a residential setting.

Ensure right to privacy, dignity and respect and freedom from coercion and restraint.

Optimize autonomy and independence in making life choices.

Facilitate choice of services and who provides them.
Provider-Owned or Controlled Residential Settings...

Individuals must have:

- A lease or other legally enforceable agreement to protect from eviction
- Privacy in their unit including entrances lockable by the individual (staff have keys as needed)
- Choice of roommates
- Freedom to furnish and decorate their unit
- Control of their schedule and activities
- Access to food at any time
- Visitors at any time
- Physical accessibility

Deviations from this rule (except accessibility) must be supported by a specific assessed need and justified in the person-centered service plan.
Person-Centered Service Planning Process Must:

Be driven by the individual and respect his/her preferences;
Include people chosen by the individual
Provide necessary information and support to ensure that the individual directs the process to the maximum extent possible
Provide discussions and information in plain language.
Reflect cultural considerations
Identify strengths, preferences, needs and desired outcomes of individual
Include individually identified goals and preferences related to relationships, community participation, employment, income and savings, healthcare and wellness, education and others
Data from NCI

WHAT DO WE KNOW ABOUT OUTCOMES AND WHERE PEOPLE LIVE?
What is NATIONAL CORE INDICATORS (NCI)?

NASDDDS, HSRI & State DD Directors

- Multi-state collaboration
- Launched in 1997 in 13 participating states – now in 45 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.
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)

2014-2015 -- Total Sample (N=24,298)
National Core Indicators (NCI) 46 Member States 2016, the District of Columbia, & County Collaborative
People Living in Independent Home/Apartment More Likely to Have Worked at Paid Community Job in Past Two Weeks
People Living in Group Homes Less Likely to Report that their Privacy is Respected
People in Independent Homes and Apartments More Likely to Make Important Decisions

- 78% Independent home or apartment, or shared with roommate
- 81% Parent or relative’s home
- 82% Community-based residence or group home
- 95% Foster care/host home

- 71% Home
- 46% With whom to live
- 56% Staff
- 61% Daily schedule
- 68% Staff
- 82% Daily schedule
People in Independent Homes and Apartments More Likely to Make Important Decisions

- Independent home or apartment, or shared with roommate:
  - Freetime: 98%
  - Day activity: 83%
  - What to buy: 96%

- Parent or relative's home:
  - Freetime: 91%
  - Day activity: 64%
  - What to buy: 83%

- Community-based residence or group home:
  - Freetime: 91%
  - Day activity: 54%
  - What to buy: 87%

- Foster care/host home:
  - Freetime: 89%
  - Day activity: 65%
  - What to buy: 86%
People in Less Structured Settings More Likely to Have Friends Who are Not Staff or Family

- ICF (N=883): 66%
- Group Home (N=4,740): 71%
- Independent home/apt (N=3,196): 79%
- Parent/relative's home (N=6,878): 73%
- Foster care/host home (N=908): 75%
- Other (N=368): 73%
Participation in the Community is Related to Where People Live

![Bar chart showing participation in community activities based on where people live.](chart.png)

- Independent home or apartment, or shared with roommate:
  - Shopping: 94%
  - Errands: 87%
  - Entertainment: 65%
- Parent or relative's home:
  - Shopping: 88%
  - Errands: 82%
  - Entertainment: 70%
- Community-based residence or group home:
  - Shopping: 87%
  - Errands: 85%
  - Entertainment: 72%
- Foster care/host home:
  - Shopping: 90%
  - Errands: 87%
  - Entertainment: 70%
Participation in the Community is Related to Where People Live

- **Independent home or apartment, or shared with roommate**
  - Out to eat: 87%
  - Religious activity: 47%
  - Exercise: 56%

- **Parent or relative's home**
  - Out to eat: 84%
  - Religious activity: 51%
  - Exercise: 56%

- **Community-based residence or group home**
  - Out to eat: 84%
  - Religious activity: 42%
  - Exercise: 52%

- **Foster care/host home**
  - Out to eat: 89%
  - Religious activity: 46%
  - Exercise: 62%
Do People Get Support to Express Preferences and Get Needed Services?

- **Person helped make service plan (N=13,896):** 86%
- **Case manager/Service Coordinator asks person what he/she wants (N=14,898):** 87%
- **Case manager/Service Coordinator helps get what person needs (N=14,258):** 86%
- **If person calls and leaves a message, case manager/service coordinator returns call right away (N= 10,992):** 71%
CONSTRAINTS TO MEETING THE REQUIREMENTS OF THE NEW RULE
Providers Identify Constraints

Licensure requires that a residential home be furnished before the license is granted & people move in – residents are unable to make choices of furnishings as a consequence.

Waiver service definitions & reimbursement require people to access community in groups which constrains choice.

Inconsistent practices and rules among providers regarding whether staff can introduce individuals to friends and family.
Providers Identify Constraints

If an individual in a residence wants to stay over with a friend in a different residence, both approved providers cannot bill.

Some providers treat visitors as volunteers and require background checks.

Some providers are considering reverse integration – is that acceptable under new HCBS expectations?

What if you have a site and building permits for a new setting?

Individuals are sometimes required to move residences when needs change rather than receiving support in current home.
How Does Guardianship Constrain Choice and Outcomes in the Rule?

NCI data show different outcomes and experiences between adults without guardianship and those with limited and full guardianships.
Experiences are Different by Legal Status

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
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
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.
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.
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.
PRACTICAL Tool for Lawyers:
Steps in Supporting Decision-Making

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.
**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](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/](http://supporteddecisions.org/amanda/)

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What did she say?