

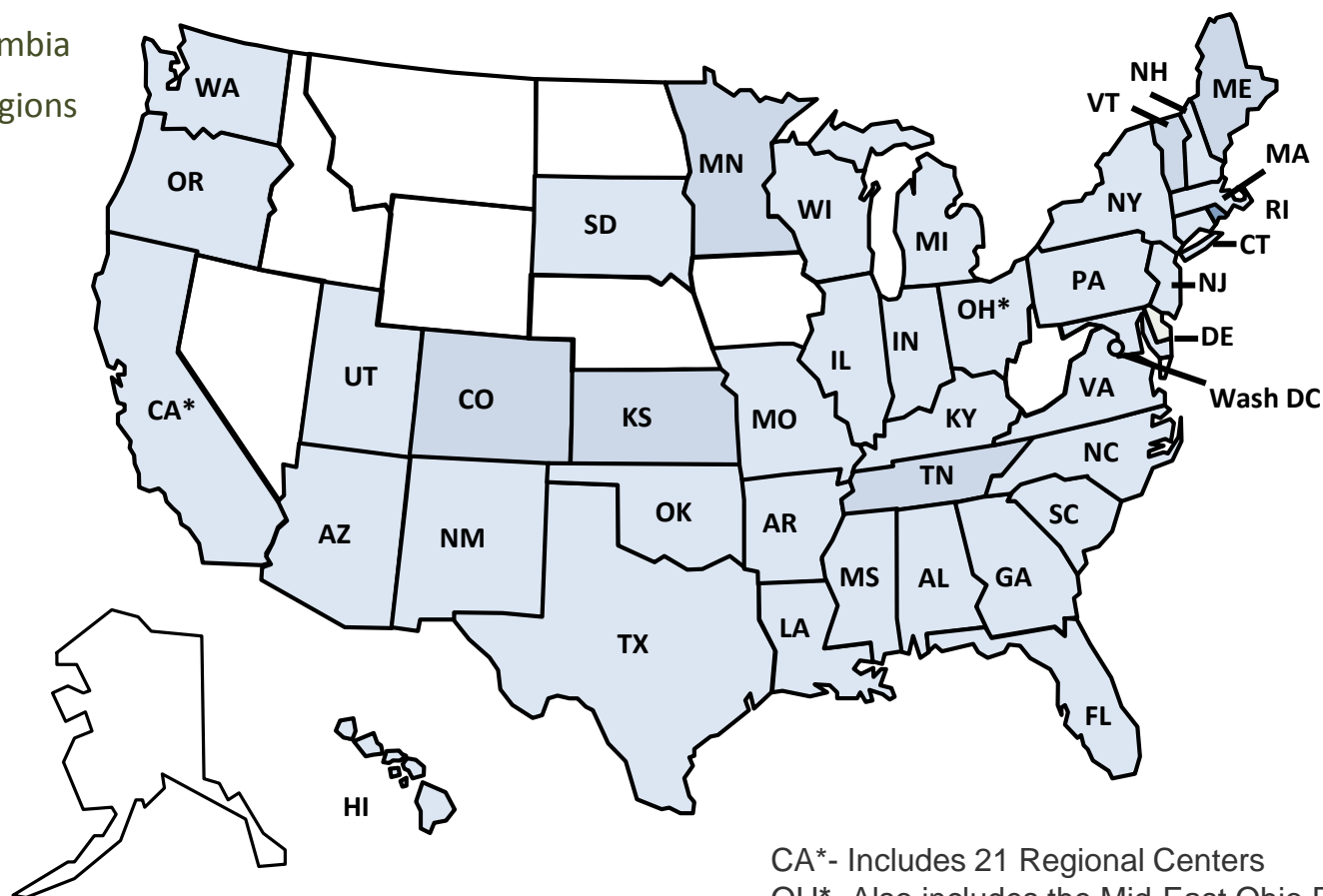
# Systems Change to Promote Rights: A Supported Decision Making Initiative and National Core Indicators Data




# National Core Indicators (NCI)

## State Members 2014-15

- 42 states
- District of Columbia
- 22 sub-state regions




# Exercising Rights

	No guardianship	Limited guardianship	Full guardianship
<b>Rights</b>			
Can be alone with friends or visitors at home	81%	75%	71%
People ask before entering home	91%	89%	88%
Uses phone or internet without restriction	92%	90%	87%


Source: NCI-DD Adult Consumer Survey data 2013-14

# Exercising Choice

 NATIONAL CORE INDICATORS™	No guardianship	Limited guardianship	Full guardianship
<b>Choice – Made decision or had some input into decision</b>			
Home	62%	46%	41%
Roommates	54%	42%	35%
Staff (day & residential)	69%	64%	60%
Daily schedule	90%	79%	77%
What to buy	93%	83%	81%


Source: NCI-DD Adult Consumer Survey data 2013-14

# Employment

 NATIONAL CORE INDICATORS™	<b>No guardianship</b>	<b>Limited guardianship</b>	<b>Full guardianship</b>
<b>Employment</b>			
Integrated employment goal in service plan	<b>30 %</b>	<b>22 %</b>	<b>21 %</b>
Had community paid job during past 2 weeks	<b>19 %</b>	<b>13 %</b>	<b>12 %</b>


Source: NCI-DD Adult Consumer Survey data 2013-14

# Relationships

	No guardianship	Limited guardianship	Full guardianship
<b>Relationships</b>			
Has friends who are not family or staff	78%	74%	73%
Can date without restrictions	71%	68%	58%

Source: NCI-DD Adult Consumer Survey data 2013-14

# Personal Characteristics

	No guardianship	Limited guardianship	Full guardianship
<b>Co-occurring:</b>			
Mild level ID	49%	33%	28%
Use speech to communicate	85%	72%	65%
Live with parents or other relatives	38%	29%	33%

Source: NCI-DD Adult Consumer Survey data from 2013-14

# NCI Guardian Status Tracking

## 2015 New Question

If under guardianship,  
guardian's relationship to  
person:

- Family
- Friend
- Employee of state or guardianship agency
- Other

## NCI 2013-14

Adults with I/DD receiving  
services in NCI states:

- No guardian - 48%
- Limited guardian - 7%
- Full guardian - 43%
- Don't know - 2%



# Massachusetts SDM Pilot

- Partnership between CPR & Nonotuck Resource Associates
- Among the first SDM demonstrations in the nation
- Individuals with I/DD enter into Agreements with supporters in areas such as health, relationships, finances, employment
  - CPR provides legal representation as necessary
  - Nonotuck care managers act as liaisons between the individual, his/her network and the community
- Advisory Council reviews progress, offers guidance
- Independent evaluation

## SDM Pilot Advisory Council

Representatives  
include:

- People using state services
- Legal scholars in disability issues
- Judges
- Attorneys
- Medical professionals
- Directors of social service organizations



# My Role as a SDM Facilitator

- Care Manager for 5 of 8 participants
- Provide information to families and supporters about SDM
- Facilitate SDM meetings with participants, CPR-Nonotuck team
- Help SDM participants understand SDM and SDM Agreement
- Assure person's voice is heard and person is satisfied
- Collect information on how SDM is used
- Participate in pilot evaluation

# My Role as an SDM Supporter

- Support decision-making: demonstration, role-playing
- One-on-one conversations laying out pros and cons
- Know how person makes decisions (for example, wait 6 minutes for Amanda's response)
- Respect person's values and preferences ... and decisions
- Lots of meetings! Lots of conversations!

## Amanda's SDM Arrangement

### Decision Support Areas:

Health care, Legal, Finances, Home and Personal Life

### Chose 4 Supporters:

- Mother
- Live in caregiver since 2009
- Respite worker
- Care Manager-friend-respite worker



# Resources

- SDM Pilot website: **[www.supporteddecisions.org](http://www.supporteddecisions.org)**  
(Website is expected to launch in July 2015.)
- SDM Pilot Handouts:
  - Representation Agreement
  - Brochure
- National Core Indicators (NCI) website: [www.nationalcoreindicators.org](http://www.nationalcoreindicators.org)
- NCI data brief on Rights & Respect. Explores extent to which public I/DD services are delivered in ways that respect service recipients' privacy, choices, and control. Highlights significant differences by race and ethnicity, guardianship status, residence type, and other variables. Presents promising innovations and programs preserving rights and respect:  
[www.nationalcoreindicators.org/resources/data-briefs](http://www.nationalcoreindicators.org/resources/data-briefs)

# Contact Us!

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