

MADISON  
HOUSE  
AUTISM  
FOUNDATION

ADDRESSING THE NEEDS OF ADULTS WITH AUTISM

2015 *Together for Choice Conference*  
Misericordia Heart of Mercy  
Chicago IL

**The State of the Nation:**  
***Accessing and Tackling the Data to Help Support Choice***



Coalition for Community Choice

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*National Coordinator, CCC*  
*Dkameka @MadisonHouseAutism.org*

# Part 1: HCBS Final Rule

- History of Policy Changes That Support Expanding Choices
- Where to find resources about Final Rule

At the end of presentation if time allows:

- What's in the Final Rule
- Guidance from CMS
- Implementation Timeline
- Next Steps



# History of Policy Changes Supporting Choice



- 1980: Home and Community Based Service waivers introduced.
  - Gives another choice to accessing support services
- 1990/2008: [Americans with Disabilities Act](#)
- *"The purposes of this Act are-*
  - (1) to carry out the ADA's objectives of providing "a clear and comprehensive national mandate for the elimination of discrimination" and "clear, strong, consistent, enforceable standards addressing discrimination" by reinstating a broad scope of protection to be available under the ADA..."*

# History of Policy Changes Supporting Choice

- 1999: The Supreme Court Olmstead Decision

*“recognition and unjustified institutional isolation of person with disabilities is a form of discrimination...”* -119 S.Ct. 2176, 2179, 2187

*“We emphasize that nothing in the ADA or its implementing regulations condones termination of institutional settings for persons unable to handle or benefit from community settings...Nor is there any federal requirement that community-based treatment be imposed on patients who do not desire it.”* -119 S. Ct. 2176, 2187



# History of Policy Changes Supporting Choice

How will the Supreme Court [Olmstead Decision](#) continue to influence housing and support choices in the future?

- The continuation of endless waiting lists, particularly for individuals who are at risk of forced institutionalization for lack of housing / waiver supports may violate Olmstead.
- State prohibition to access of waiver funding in a person's chosen residence and/or least restrictive setting that would otherwise put them at risk of institutionalization may violate Olmstead.
- Lack of affordable, accessible housing resulting in the risk of or forced institutionalization may violate Olmstead.

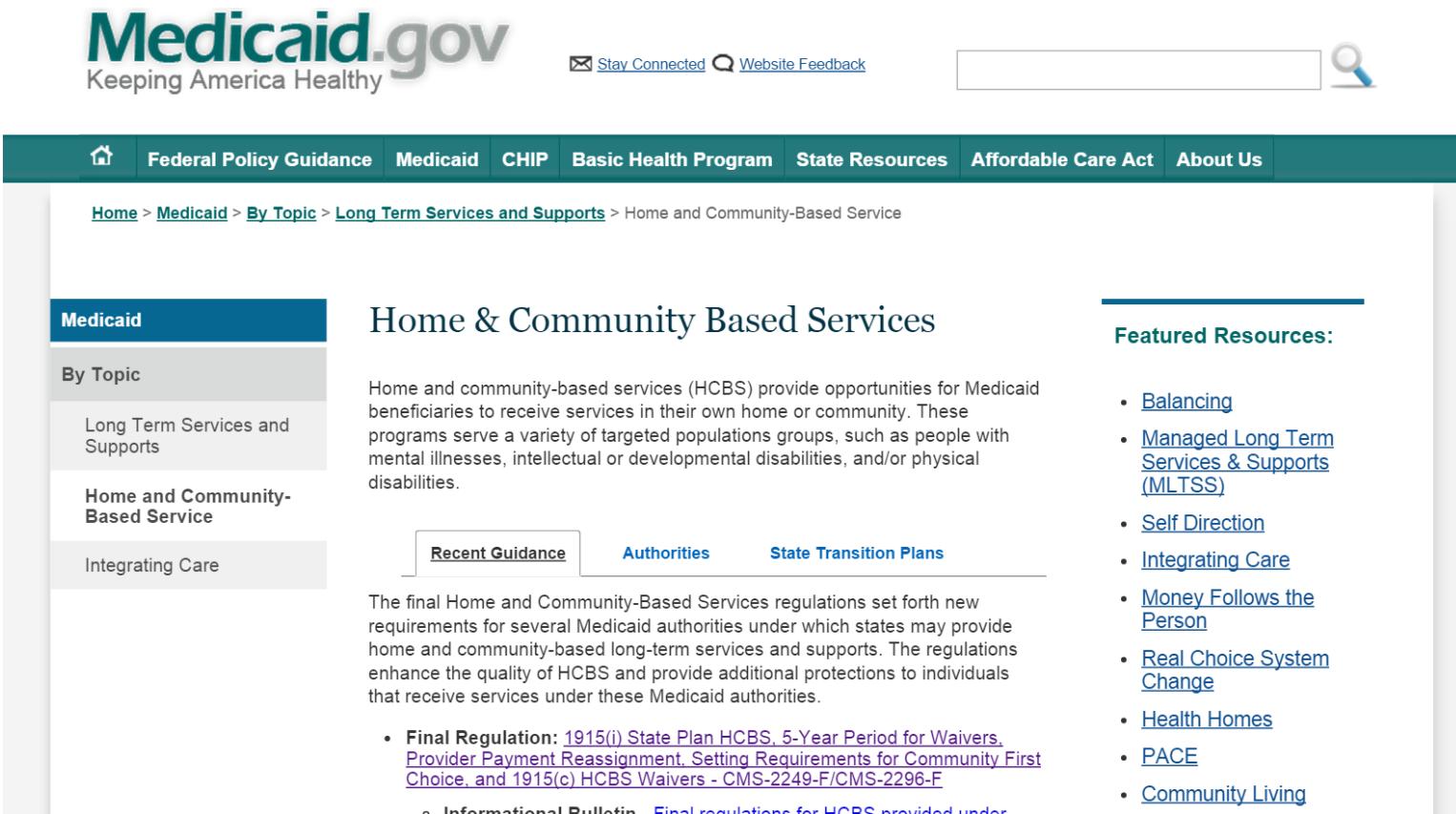


# History of Policy Changes Supporting Choice

- 2000: [Developmental Disabilities Assistance and Bill of Rights Act](#):
  - *“assure that individuals with developmental disabilities and their families participate in the design of and have access to needed community services, individualized supports, and other forms of assistance that promote self-determination, independence, productivity, and integration and inclusion in all facets of community life ...”* - 42 U.S.C. 15001 (b) (2006)
- 2014: [CMS HCBS Final Rule](#) based on outcome-oriented criteria with an emphasis on person-centered planning and community access.
  - *“In this Final Rule, CMS is moving away from defining home and community settings by “what they are not” and toward defining them by the nature and quality of individuals experiences. The home and community-based setting provisions in this final rule establish a more outcome-oriented definition of home and community-based settings, rather than one based solely on a setting’s location, geography, or physical characteristics.”* –[CMS Final Rule Q&A](#)

# Where to Find Resources on HCBS Final Rule

[Medicaid website](#) gives links to Final Rule, CMS guidance documents, State Transition Plans, and any official correspondence between states and CMS regarding the State Transition Plans:



The screenshot shows the Medicaid.gov homepage with a navigation bar at the top. The main content area is titled "Home & Community Based Services" and discusses HCBS regulations. A sidebar on the left lists "Medicaid" categories: "By Topic" (Long Term Services and Supports, Home and Community-Based Service, Integrating Care), "Recent Guidance", "Authorities", and "State Transition Plans". A "Featured Resources" sidebar on the right lists various links related to HCBS.

**Medicaid.gov**  
Keeping America Healthy

Stay Connected [Website Feedback](#)

[Home](#) > [Medicaid](#) > [By Topic](#) > [Long Term Services and Supports](#) > Home and Community-Based Service

**Medicaid**

By Topic

Long Term Services and Supports

Home and Community-Based Service

Integrating Care

Recent Guidance

Authorities

State Transition Plans

Home & Community Based Services

Home and community-based services (HCBS) provide opportunities for Medicaid beneficiaries to receive services in their own home or community. These programs serve a variety of targeted populations groups, such as people with mental illnesses, intellectual or developmental disabilities, and/or physical disabilities.

The final Home and Community-Based Services regulations set forth new requirements for several Medicaid authorities under which states may provide home and community-based long-term services and supports. The regulations enhance the quality of HCBS and provide additional protections to individuals that receive services under these Medicaid authorities.

- Final Regulation: [1915\(i\) State Plan HCBS, 5-Year Period for Waivers, Provider Payment Reassignment, Setting Requirements for Community First Choice, and 1915\(c\) HCBS Waivers - CMS-2249-F/CMS-2296-F](#)
- Informational Bulletin - Final regulations for HCBS provided under

**Featured Resources:**

- [Balancing](#)
- [Managed Long Term Services & Supports \(MLTSS\)](#)
- [Self Direction](#)
- [Integrating Care](#)
- [Money Follows the Person](#)
- [Real Choice System Change](#)
- [Health Homes](#)
- [PACE](#)
- [Community Living](#)



# Where to Find Resources on HCBS Final Rule

## Medicaid website :

Complete Final Rule.  
First ~70 pages is  
CMS responses to  
public comment of  
NPRM's

CMS webinar that  
gives overview of  
Final Rule

Q&A  
about the  
Final Rule  
in general

**Recent Guidance**   **Authorities**   **State Transition Plans**

The final Home and Community-Based Services regulations set forth new requirements for several Medicaid authorities under which states may provide home and community-based long-term services and supports. The regulations enhance the quality of HCBS and provide additional protections to individuals that receive services under these Medicaid authorities.

- **Final Regulation:** [1915\(i\) State Plan HCBS, 5-Year Period for Waivers, Provider Payment Reassignment, Setting Requirements for Community First Choice, and 1915\(c\) HCBS Waivers - CMS-2249-F/CMS-2296-F](#)
  - **Informational Bulletin** - [Final regulations for HCBS provided under Medicaid's 1915\(c\), 1915\(i\) and 1915\(k\) authorities](#) 
  - **Press Release** - [Final regulations for HCBS provided under Medicaid's 1915\(c\), 1915\(i\) and 1915\(k\) authorities](#)
  - **Fact Sheets Regarding Final Regulation CMS-2249-F/CMS-2296-F**
    - [Overview of Regulation](#) 
    - [1915\(c\): Changes to HCBS Waiver Program](#) 
    - [1915\(i\): Key Provisions for HCBS State Plan Option](#) 
    - [Summary of Key Provisions of the HCBS Settings Final Rule](#) 
    - [HCBS Final Rule Webinar Presentation Download](#) 
    - [Final Rule: Questions and Answers](#) 

▶ **Settings Requirements Compliance Toolkit**

▶ **Additional Resources**

- [Self Direction](#)
- [Integrating Care](#)
- [Money Follows the Person](#)
- [Real Choice System Change](#)
- [Health Homes](#)
- [PACE](#)
- [Community Living](#)
- [Workforce](#)

*Information provided by the  
Disabled and Elderly Health  
Programs Group. To request  
clarifications please contact  
[hcbs@cms.hhs.gov](mailto:hcbs@cms.hhs.gov).*

CMS email for  
questions and  
concerns

# Where to Find Resources on HCBS Final Rule

## Examples of comments section in Final Rule offers guidance and evidence that CMS supports choice:

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*Comment:* A number of individual commenters shared personal stories expressing satisfaction with their current living arrangements and displeasure that new regulations might force them to move or dictate where they should live. One person wrote, "Please allow Medicaid waivers to continue to pay for services in planned communities similar to retirement communities. I want to live in a community with my friends." Another noted, "I believe this proposed rule would . . . deny access to residential care and assisted living for those who need it most." Many commenters talked about the importance of retaining freedom of choice. One commenter stated, ". . . what I am advocating is CHOICE. We should be expanding options rather than narrowing possibilities and options, and we should ask those with disabilities and their families what they want, not what others think they want." Finally, quite a few commenters echoed a warning to stay away from a "one size fits all"

le.  
the

person-centered plan, personal outcomes and satisfaction.

*Response:* We very much appreciate hearing personal stories as they help us better understand how our proposed actions will affect individuals receiving services under the HCBS waiver program. We believe that individual choice is important and have worked to promote choice in the final rule. In addition, it is important to note that HCBS waiver funding is only one way in which federal Medicaid finances long term services and supports; a setting that may not meet the HCB definition may still qualify for Medicaid financing, but not as a home and community based service.

We agree that the definition we included in the proposed rule for HCBS settings may have had the result of restricting the settings in which HCB waiver services can be provided in a way that we did not intend and in narrowing choices for participants. The final rule is more flexible and less prescriptive in that it does not preclude certain settings per se but rather establishes affirmative, outcome-based criteria for defining whether a setting is or is not home and community-based. The language in the final rule specifies that any setting that is located in a

Pg 2961:

and individuals are fully informed of their rights.

*Comment:* One commenter wanted to know if it is the responsibility of the provider to assist the individual in finding other housing, services, and supports.

*Response:* The state is responsible for addressing this assistance through the person-centered planning process.

*Comment:* One commenter recommends the regulation require that

3012

Federal Register / Vol. 79, No.

that we will continue to be discerning about what types of settings qualify for waiver funds. We are including language in the final rule that focuses on the critical role of person-centered planning and addresses fundamental protections regarding freedom, dignity, control, daily routines, privacy and community integration.

*Comment:* A number of commenters

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Coalition for Community Choice

# Where to Find Resources on HCBS Final Rule

## Medicaid website :

Summary of fully compliant setting regulations

CMS guidance, NOT part of the Final Rule!

Q&A for HCBS settings and public comment requirements

Helps clarify the higher scrutiny process

### ▼ Settings Requirements Compliance Toolkit

CMCS is pleased to share with State Medicaid Agencies, Operating Agencies, and other stakeholders a Home and Community-Based Settings Toolkit to assist states develop Home and Community-Based 1915(c) waiver and 1915(i) SPA amendment or renewal application(s) to comply with new requirements in the recently published Home and Community Based Services' (HCBS) regulations. The toolkit includes:

- A [summary of the regulatory requirements](#) of fully compliant HCB settings and those settings that are excluded.
- Schematic drawings of the [heightened scrutiny process](#) as a part of the regular waiver life cycle and the [HCBS 1915\(c\) compliance flowchart](#).
- Additional technical guidance on regulatory language regarding [settings that isolate](#).
- Exploratory questions that may assist states in the assessment of:
  - [Residential Settings](#)
  - [Non-Residential Settings](#)
- [Questions and Answers Regarding Home and Community-Based Settings](#)
- [Statewide Transition Plan Toolkit](#) for Alignment with HCB Settings Regulation Requirements Suggestions for alternative approaches and considerations for states as they prepare and submit Statewide Transition Plans for the new federal requirements for residential and non-residential home and community-based settings. The regulatory requirements can be found at 42 CFR 441.301(c)(4)(5) and 441.710(a)(1)(2).
- [HCBS Basic Element Review Tool for Statewide Transition Plans and HCBS Content Review Tool for Statewide Transition Plans](#)
- [Frequently Asked Questions Regarding the Heightened Scrutiny Review Process and Other Home and Community-Based Settings Information](#)

CMS questions to consider in determining if settings have HCB characteristics

# Where to Find Resources on HCBS Final Rule

## 'Summary of regulatory requirements on fully compliant HCBS settings':

### Regulatory Requirements for Home and Community-Based Settings:

For 1915(c) home and community-based waivers and, for 1915(i) State plan home and community-based services, home and community-based settings must have all of the following qualities defined at §441.301(c)(4) and §441.710 respectively, and such other qualities as the Secretary determines to be appropriate, based on the needs of the individual as indicated in their person-centered service plan:

- The setting is integrated in and supports full access of individuals receiving Medicaid HCBS to the greater community, including opportunities to seek employment and work in competitive integrated settings, engage in community life, control personal resources, and receive services in the community, to the same degree of access as individuals not receiving Medicaid HCBS.
- The setting is selected by the individual from among setting options including non-disability specific settings and an option for a private unit in a residential setting. The setting options are identified and documented in the person-centered service plan and are based on the individual's needs, preferences, and, for residential settings, resources available for room and board.
- Ensures an individual's rights of privacy, dignity and respect, and freedom from coercion and restraint.
- Optimizes, but does not regiment, individual initiative, autonomy, and independence in making life choices, including but not limited to, daily activities, physical environment, and with whom to interact.
- Facilitates individual choice regarding services and supports, and who provides them.
- In a provider-owned or controlled residential setting, in addition to the qualities specified above, the following additional conditions must be met:

1. The unit or dwelling is a specific physical place that can be owned, rented, or occupied under a legally enforceable agreement by the individual receiving services, and the individual has, at a minimum, the same responsibilities and protections from eviction that tenants have under the landlord/tenant law of the state, county, city, or other

6. Any modification of the additional conditions specified in items 1 through 4 above, must be supported by a specific assessed need and justified in the person-centered service plan. The following requirements must be documented in the person-centered service plan:

- Identify a specific and individualized assessed need.
- Document the positive interventions and supports used prior to any modifications to the person-centered service plan.
- Document less intrusive methods of meeting the need that have been tried but did not work.
- Include a clear description of the condition that is directly proportionate to the specific assessed need.
- Include regular collection and review of data to measure the ongoing effectiveness of the modification.
- Include established time limits for periodic reviews to determine if the modification is still necessary or can be terminated.
- Include the informed consent of the individual.
- Include an assurance that interventions and supports will cause no harm to the individual.

# Where to Find Resources on HCBS Final Rule

## Settings That are Not Home and Community-Based:

For 1915(c) home and community-based waivers, settings that are not home and community-based are defined at §441.301(c)(5) as follows:

- A nursing facility;
- An institution for mental diseases;
- An intermediate care facility for individuals with intellectual disabilities;
- A hospital; or
- Any other locations that have qualities of an institutional setting, as determined by the Secretary.

For 1915(i) State plan home and community-based services, settings that are not home and community-based are defined at §441.710(a)(2) as follows:

- A nursing facility;
- An institution for mental diseases;
- An intermediate care facility for individuals with intellectual disabilities;
- A hospital; or
- Any other locations that have qualities of an institutional setting, as determined by the Secretary.

# Where to Find Resources on HCBS Final Rule

## **Settings that are Presumed to have the Qualities of an Institution:**

For 1915(c) home and community-based waivers, section 441.301(c)(5)(v) specifies that the following settings are presumed to have the qualities of an institution:

- any setting that is located in a building that is also a publicly or privately operated facility that provides inpatient institutional treatment,
- any setting that is located in a building on the grounds of, or immediately adjacent to, a public institution, or
- any other setting that has the effect of isolating individuals receiving Medicaid HCBS from the broader community of individuals not receiving Medicaid HCBS.

For 1915(i) State plan home and community-based services, section 441.710(a)(2)(v) specifies that the following settings are presumed to have the qualities of an institution:

- any setting that is located in a building that is also a publicly or privately operated facility that provides inpatient institutional treatment,
- any setting that is located in a building on the grounds of, or immediately adjacent to, a public institution, or
- any other setting that has the effect of isolating individuals receiving Medicaid HCBS from the broader community of individuals not receiving Medicaid HCBS.

# Where to Find Resources on HCBS Final Rule

CMS Guidance (NOT Final Rule): “List of examples of residential settings that typically have the effect of isolating individuals receiving HCBS from the broader community:”

- Farmsteads or disability-specific farm community
- Gated/secured “community” for people with disabilities
- Residential schools
- Multiple setting co-located and operationally related



# Where to Find Resources on HCBS Final Rule

[Medicaid website :](#)

[Home](#) [Federal Policy Guidance](#) [Medicaid](#) [CHIP](#) [Basic Health Program](#) [State Resources](#) [Affordable Care Act](#) [About Us](#)

[Home](#) > [Medicaid](#) > [By Topic](#) > [Long Term Services and Supports](#) > Home and Community-Based Service

**Medicaid**

**By Topic**

- Long Term Services and Supports
- Home and Community-Based Service**
- Integrating Care

[Recent Guidance](#) [Authorities](#) [State Transition Plans](#)

Home and community-based services (HCBS) provide opportunities for Medicaid beneficiaries to receive services in their own home or community. These programs serve a variety of targeted populations groups, such as people with mental illnesses, intellectual or developmental disabilities, and/or physical disabilities.

The [final HCBS regulation](#) published January 26, 2014, requires states operating a section 1915(c) waiver or a section 1915(i) state plan benefit (that was in effect on or before March 17, 2014) to submit a statewide transition plan addressing compliance with the regulation. More information about this plan is available in the [Statewide Transition Plan Toolkit for Alignment with HCBS Settings Regulation Requirements](#).

In an effort to keep stakeholders apprised of the status of HCBS Statewide Transition Plans (STP), the following documents will be posted on the [Statewide Transition Plans](#) page, as they become available or are sent to states:

1. Proposed Plan URL: The URL link to the STP the state submitted to CMS.
2. CMIA: Clarifications and/or Modifications required for Initial Approval: The communication CMS sends to the state notifying the state that public

**Featured Resources:**

- [Balancing](#)
- [Managed Long Term Services & Supports \(MLTSS\)](#)
- [Self Direction](#)
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- [Health Homes](#)
- [PACE](#)
- [Community Living](#)
- [Workforce](#)

1) CLICK THIS TAB  
to change the  
information  
displayed

2) CLICK THIS LINK  
to get to page with  
STP and CMIA

# Where to Find Resources on HCBS Final Rule

## Medicaid website :

Home > Medicaid > By Topic > Long Term Services and Supports > Home and Community-Based Service

### Medicaid

#### By Topic

- Long Term Services and Supports
- Home and Community-Based Service
- Integrating Care

### Statewide Transition Plans (STP)

The table below provides all available documents related to Statewide Transition Plans. The table will be updated as states submit additional documents and additional documents are available from CMS. More information about the statewide transition plans and the final HCBS regulation published January 26, 2014, is available under Recent Guidance on the [HCBS](#) page.

State	Proposed Plan URL <sup>1</sup>	CMIA <sup>2</sup>	Initial Approval <sup>3</sup>	Final Approval <sup>4</sup>	Approved Plan <sup>5</sup>
Alabama	<a href="#">Available</a>	<a href="#">Available</a>	<a href="#">Available</a>		
Alaska	<a href="#">Available</a>	<a href="#">Available</a>			
Arizona					
Arkansas	<a href="#">Available</a>	<a href="#">Available</a>			
California	<a href="#">Available</a>				
Colorado	<a href="#">Available</a>	<a href="#">Available</a>			
Connecticut	<a href="#">Available</a>	<a href="#">Available</a>			
Delaware	<a href="#">Available</a>	<a href="#">Available</a>			
District of Columbia	<a href="#">Available</a>	<a href="#">Available</a>			
Florida	<a href="#">Available</a>	<a href="#">Available</a>	<a href="#">Available</a>		

State Transition Plan submitted by your state including summary of public comments, **not yet approved**.

Clarifications and/or Modifications required for Initial Approval (CMIA), look for deadlines!

# What to do with Resources on HCBS Final Rule

## Important Next Steps:

1. **Read the HCBS Final Rule setting requirements**
2. **Read the CCC Mini-Toolkit for tips on what to look for in STP**
3. **Read your STP and CMIA and use the CCC Mini-Toolkit to get involved**
4. **LIKE the CCC Facebook Page**
5. **Join the CCC!**

**COALITION for COMMUNITY CHOICE:  
GUIDANCE FOR STATES IMPLEMENTING CMS-2249-F/2296-F**

The Coalition For Community Choice Urges States to Support Expanding, Not Limiting, Home, Community and Employment Options Based on Individual Experiences, Choices and Support Needs, from a Full Array of Options. In March 2014, the Centers for Medicare & Medicaid Services (CMS) released final regulations for home and community-based services (HCBS) provided through its 1915(c) HCBS Waiver program, 1915(i) HCBS State Plan Option, and 1915(k) Community First Choice Option. CMS regulations ensure supports funded by HCBS waivers are person-centered and assessed based on the experiences of individuals with disabilities receiving them. The burden now remains on States, with the intent to demonstrate that housing, employment, and support service settings are compliant with the regulations that do not limit residential and meaningful work opportunities and settings that family caregivers who are often excluded from opportunities. The need is significant: over the age of 60 who will family home in

**HCBS FINAL RULE  
And State Transition Plan Resource Reference**

If you haven't already, please consider joining the Coalition for Community Choice as an individual or request an application to join our network of organization and business leaders. Please email the National Coordinator, Desiree Kameka, at [DKameka@MadisonHouseAutism.org](mailto:DKameka@MadisonHouseAutism.org)

**FINAL RULE RELEASED**  
In January 2014, the Center for Medicaid & Medicare Services (CMS) released the much anticipated Final Rule regarding Home and Community Based Service (HCBS) waivers. This [powerpoint](#) created by federal CMS staff gives an overview of the Final Rule. You can also read the [Final Rule](#) in the Federal Registrar.

- The Final Rule was developed to significantly improve the individualized supports and help the support system become more person centered with fewer conflicts of interest. Characteristics of how the community in the regulations are outcome oriented and based on the waiver recipients quality of life and any physical characteristics.
- States have the authority to implement more stringent regulations, therefore it is important to be part of the State Transition process to ensure the state is continuing to represent the HCBS needs and setting controls for their citizens with I/DD.
- This 2-page [HCBS Final Rule Policy Brief](#) and [FAQ about the Final Rule](#) can be used to educate others about the HCBS Final Rule.



Coalition for Community Choice

# Where to Find Resources on HCBS Final Rule



nitvchoice.org/ccc-materials/

Welcome to the Coalition for Community Choice

[www.CoalitionForCommunityChoice.org](http://www.CoalitionForCommunityChoice.org)



**Contents [hide]**

- 1 CCC Principles
- 2 CCC Policy Brief: New HCBS Regulations
- 3 Frequently Asked Questions About the New HCBS Regulations
- 4 CCC Guidance to State Leaders for Implementing Their State Transition Plan
- 5 "What Intentional Communities Are and Are Not"

**CCC Principles**  
This handout provides list the CCC Principles and can be shared with individual advocates and organizations who may want to join the CCC. It also contains CCC contact information.

[CLICK HERE TO VIEW PDF](#)

**CCC Policy Brief: New HCBS Regulations**  
In January 2014, new regulations were released that influence waiver funding, generally called Home and Community Based Service (HCBS) waivers. These waivers are different in every state, but are the main source of funding for long term support services for individuals with disabilities. This two-page CCC Policy Brief explains the implications these new regulations may have on housing and employment choices.

[CLICK HERE TO VIEW PDF](#)

## Additional resources for members only:

- Monthly newsletters
- Conference Calls
- Toolkits and Calls to Action
- Technical Assistance from National Coordinator



# Part 2: Finding Statistics to Support Choice

- Demonstrate the real growth gap of LTSS in your state
- Demonstarte inaccess to affordable housing for those with I/DD in your state
- Explore quality of life assesments for those with I/DD in your state
- Demonstrate abuse is occurring “in community” and offer reports of victems with I/DD in your state

# LTSS Supply & Demand: State of the States in I/DD 2015 Report



## The State of the States in Developmental Disabilities

University of Colorado  
BOULDER | COLORADO SPRINGS | DENVER | ANSCHUTZ MEDICAL CAMPUS



### STATE OF THE STATES IN DEVELOPMENTAL DISABILITIES

#### Welcome

#### What's New

Welcome to the website for the ***State of the States in Developmental Disabilities Project***, administered by the University of Colorado. The Project is funded in part by the [Administration on Intellectual and Developmental Disabilities](#), U.S. Department of Health and Human Services.

INTELLECTUAL AND DEVELOPMENTAL DISABILITIES

- What's New!
- State of the States
- Intellectual/Developmental Disabilities
  - Create a Chart
  - State Profiles
- AIDD Projects of National Significance: Longitudinal Data Collection
- Cross Disability
  - Overview
  - Create a Chart
- About Us
- Publications
- Coleman Institute for

- Dr. David Braddock has been publishing this report for decades, tracks over 35 years of data on residential supports and settings.
- Full 2015 Report available in print only, not digital.
- [State Profiles](#)



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# LTSS Supply & Demand: State of the States in I/DD 2015 Report



## The State of the States in Developmental Disabilities

University of Colorado

BOULDER | COLORADO SPRINGS | DENVER | ANSCHUTZ MEDICAL CAMPUS

### State Profiles for I/DD Spending During Fiscal Years 1977-2013

Select a state from the map to download a graphic profile in pdf format, or visit [Create a Chart](#) to make charts on-line.



Select a State ▼

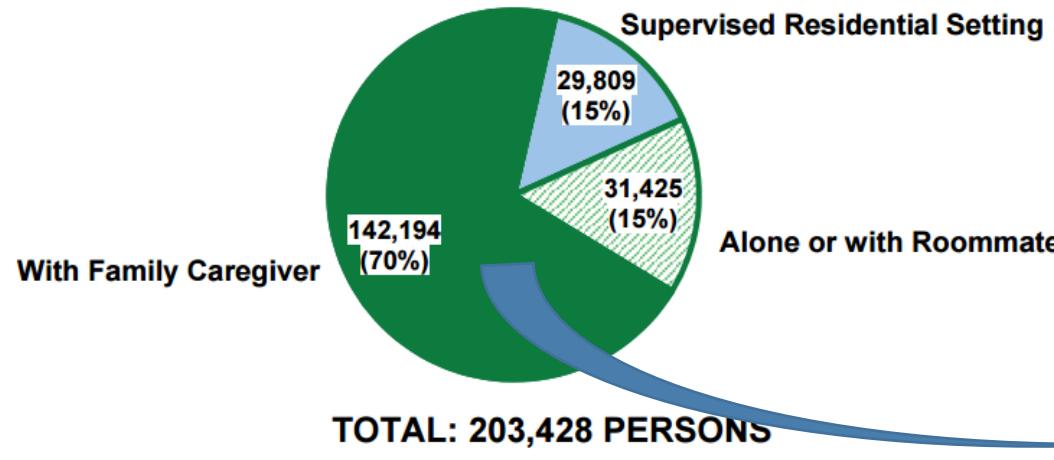
[View the United States profile](#)

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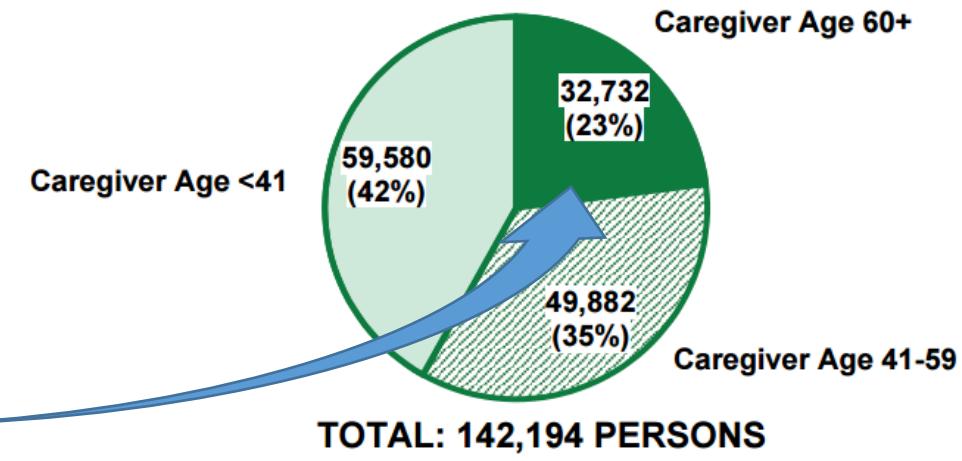
- [Click on your state to see its profile.](#)
- Jump to Page 6 first!

# LTSS Supply & Demand: State of the States in I/DD 2015 Report

ESTIMATED NUMBER OF INDIVIDUALS WITH I/DD BY LIVING ARRANGEMENT: FY 2013



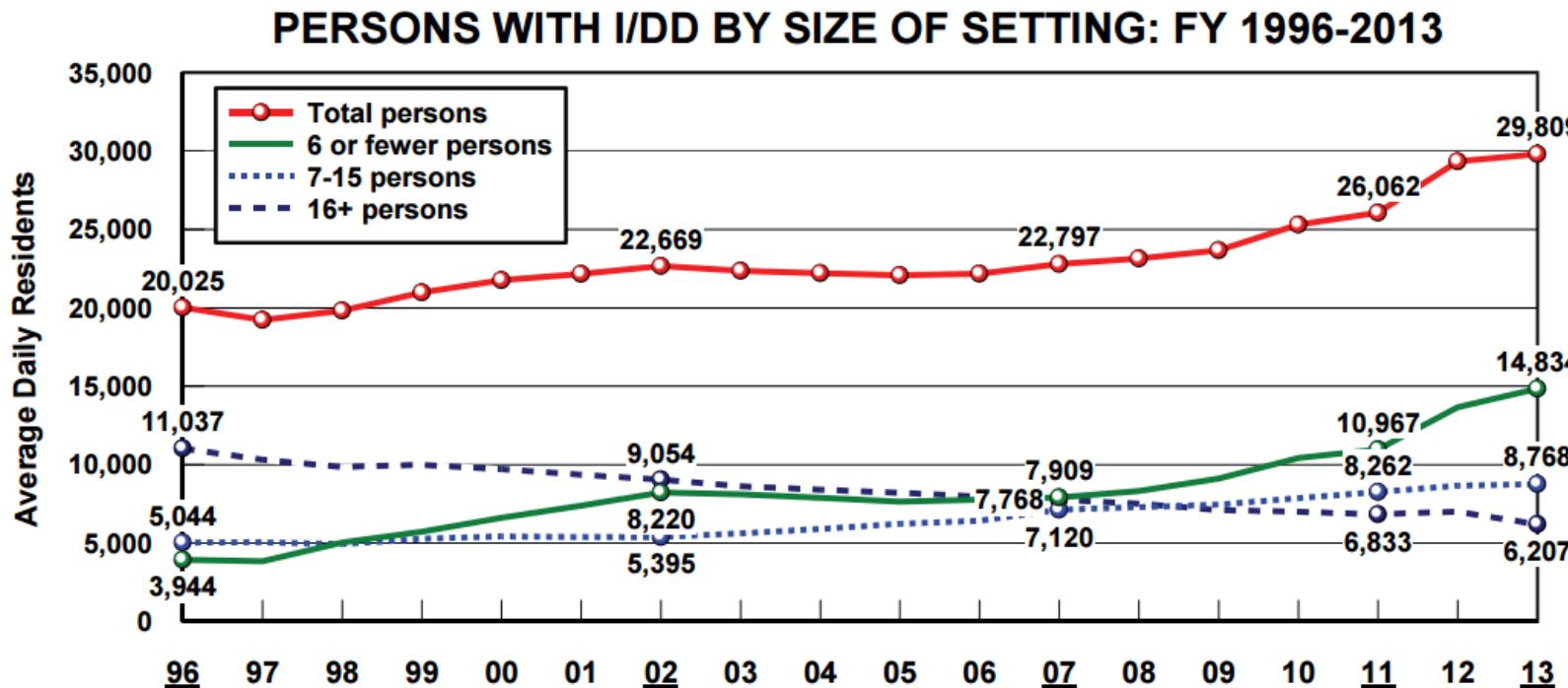
ESTIMATED NUMBER OF INDIVIDUALS WITH I/DD BY AGE GROUP LIVING WITH FAMILY CAREGIVERS: FY 2013



Page 6, using IL profile as an example:

- Identify how many individuals with I/DD are living with **family caregivers** =  $70\% / 142,194$
- Identify how many individuals with I/DD are living with **family caregivers over the age of 60** =  $32,732$

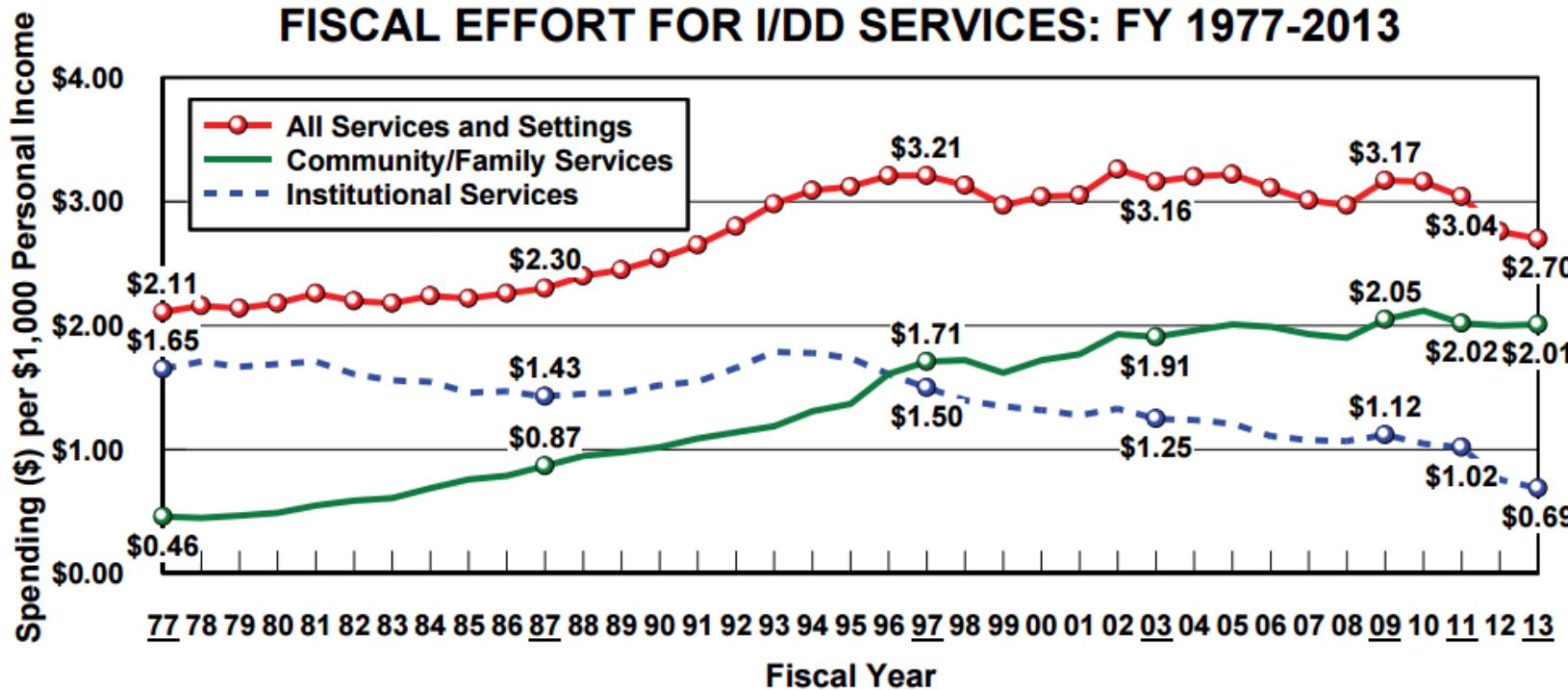
# LTSS Supply & Demand: State of the States in I/DD 2015 Report



**IMPORTANT QUESTION:** If the growth rate of residential supports is approximately 575 individuals a year, how does the state plan to meet the demand of 33,000 who will soon lose their primary caregiver, their elder parents?

- [Page 3 using IL profile](#),  
Find growth rate:  
 $29,809 - 20,025 = 9,784$
- In 17 years, less than 10,000 individuals with I/DD were given residential supports to move out of their family home.
- IL must triple growth in half the time just to meet the needs of those with I/DD living with aging family caregivers.

# LTSS Supply & Demand: State of the States in I/DD 2015 Report

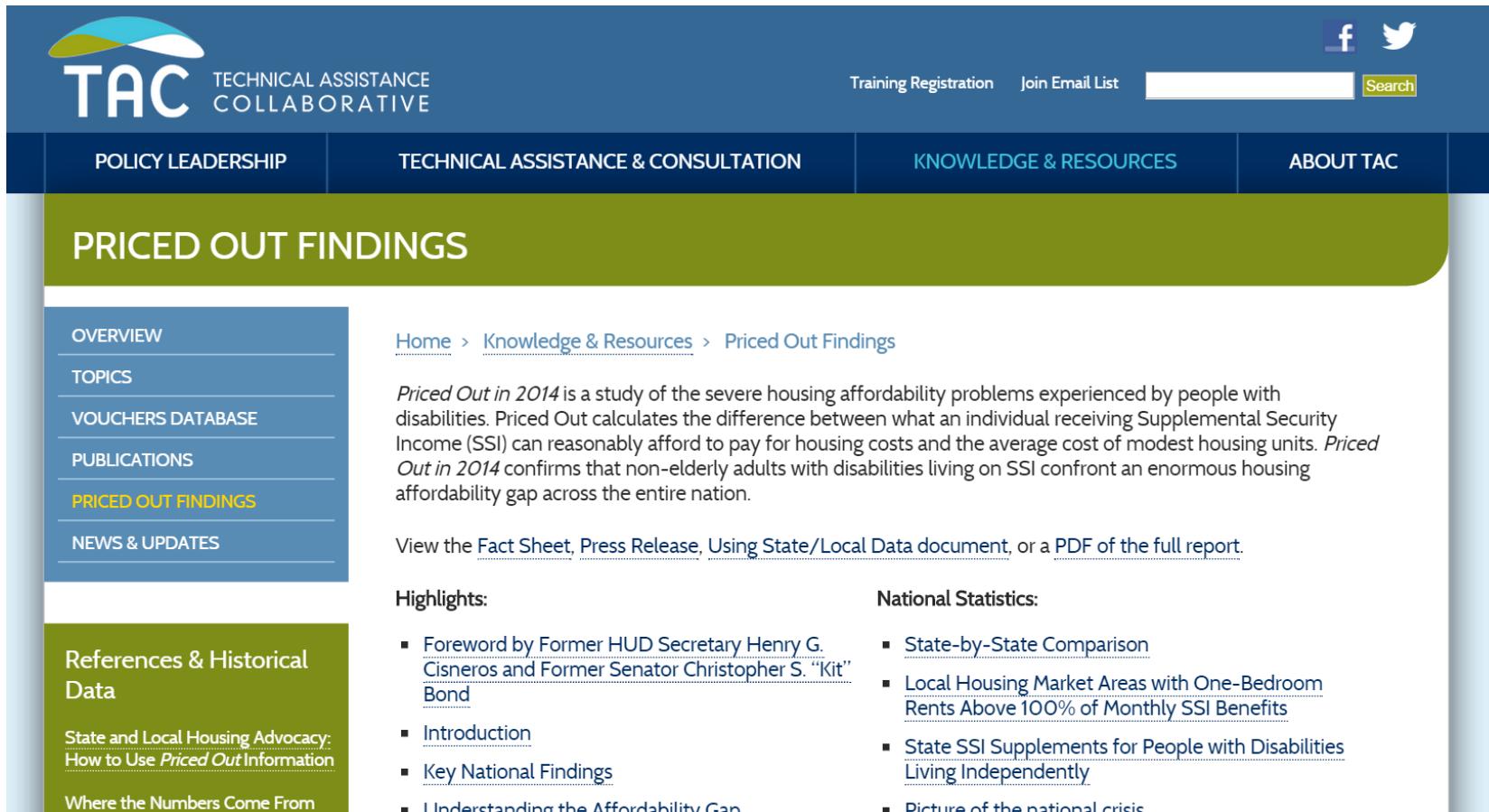


Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2014.

**IMPORTANT QUESTION:** Do you think Illinois citizens would vote to allocate \$5 of every \$1000 taxed for their neighbors with I/DD to have access to the supports they need?

- Page 1 using IL profile, \$2.70 of every \$1000 of taxpayer money is going to support those with I/DD in IL.
- Since 1977, the burden of costs for taxpayers as increased only .59 cents for every \$1000 of taxable income, and has declined significantly since 2009

# Access to Housing: *Priced Out in 2014*



The screenshot shows the homepage of the Technical Assistance Collaborative (TAC) website. The header features the TAC logo with a stylized sun icon, the text 'TECHNICAL ASSISTANCE COLLABORATIVE', and social media links for Facebook and Twitter. Below the header, there are four main navigation tabs: 'POLICY LEADERSHIP', 'TECHNICAL ASSISTANCE & CONSULTATION', 'KNOWLEDGE & RESOURCES', and 'ABOUT TAC'. A large green banner across the middle of the page reads 'PRICED OUT FINDINGS'. On the left, a sidebar menu lists 'OVERVIEW', 'TOPICS', 'VOUCHERS DATABASE', 'PUBLICATIONS', 'PRICED OUT FINDINGS' (which is highlighted in yellow), and 'NEWS & UPDATES'. The main content area contains a breadcrumb navigation ('Home > Knowledge & Resources > Priced Out Findings'), a paragraph about the 'Priced Out in 2014' study, and links to 'Fact Sheet', 'Press Release', 'Using State/Local Data document', and a 'PDF of the full report'. Below this, sections for 'Highlights' and 'National Statistics' are listed with their respective links.

**PRICED OUT FINDINGS**

OVERVIEW  
TOPICS  
VOUCHERS DATABASE  
PUBLICATIONS  
**PRICED OUT FINDINGS**  
NEWS & UPDATES

References & Historical Data  
State and Local Housing Advocacy: How to Use *Priced Out* Information  
Where the Numbers Come From

Home > Knowledge & Resources > Priced Out Findings

*Priced Out in 2014* is a study of the severe housing affordability problems experienced by people with disabilities. Priced Out calculates the difference between what an individual receiving Supplemental Security Income (SSI) can reasonably afford to pay for housing costs and the average cost of modest housing units. *Priced Out in 2014* confirms that non-elderly adults with disabilities living on SSI confront an enormous housing affordability gap across the entire nation.

View the [Fact Sheet](#), [Press Release](#), [Using State/Local Data document](#), or a [PDF of the full report](#).

**Highlights:**

- [Foreword by Former HUD Secretary Henry G. Cisneros and Former Senator Christopher S. "Kit" Bond](#)
- [Introduction](#)
- [Key National Findings](#)
- [Understanding the Affordability Gap](#)

**National Statistics:**

- [State-by-State Comparison](#)
- [Local Housing Market Areas with One-Bedroom Rents Above 100% of Monthly SSI Benefits](#)
- [State SSI Supplements for People with Disabilities Living Independently](#)
- [Picture of the national crisis](#)

- [Priced Out in 2014](#) shows that individuals with disabilities can not afford housing without assistance.
- **Housing Choice Vouchers and Section 8/811 projects can not meet the demand.**
- **Report broken down into counties.**

# Access to Housing: *Priced Out in 2014*



**References & Historical Data**

- State and Local Housing Advocacy: How to Use *Priced Out* Information
- Where the Numbers Come From
- Acknowledgements
- Historical *Priced Out* Data (1998-2012)

**Findings:**

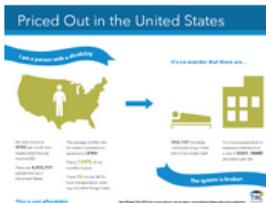
- Foreword by Former HUD Secretary Henry G. Cisneros and Former Senator Christopher S. "Kit" Bond
- Introduction
- Key National Findings
- Understanding the Affordability Gap
- TAC/CCD Federal Policy Recommendations

**National Statistics:**

- State-by-State Comparison
- Local Housing Market Areas with One-Bedroom Rents Above 100% of Monthly SSI Benefits
- State SSI Supplements for People with Disabilities Living Independently
- Picture of the national crisis

*Priced Out in the United States*

Please review the results in the table below or [click here](#) for a picture of the crisis in Illinois.



Metropolitan Statistical Area (MSA)	SSI Monthly Payment	SSI as % of Median Income	% SSI for 1BR Apt.	% SSI for Efficiency Apt.	Year
Chicago/Joliet/Naperville	\$721	17.1%	128%	113%	2014
Statewide	\$721	18.1%	111%	96%	2014
National	\$750	20.1%	104%	90%	2014

- Even if an individual can access waiver supports, they can not afford to pay for housing without housing assistance in any part of the state.



**IMPORTANT QUESTION:** How does the state plan to increase the affordable housing supply of 33,000 individuals with I/DD who otherwise will be forcefully institutionalized or left homeless for lack of affordable, accessible housing?

# Access to Housing: *Priced Out in 2014*

## Priced Out in Illinois

*I am a person with a disability*

My only income is  
**\$721** per month from  
Supplemental Security  
Income (SSI)

There are **173,206**  
people like me in  
Illinois

The average monthly rent  
for a basic one-bedroom  
apartment is **\$797**

That is **111%** of my  
monthly income



I have **no** money left  
for food, transportation,  
clothing, and other things  
I need

*It's no wonder that there are...*



**7,350** homeless indi-  
viduals living in shelters  
on any single night



Too many people are stuck  
in expensive institutions at  
a cost of **\$226 - \$422**  
per person per day

*The system is broken*

**This is not affordable**

See *Priced Out 2014* at [www.tacinc.org](http://www.tacinc.org) to learn more about these alarming statistics

Fact sheet offers good suggestions,  
but additionally, policy barriers can  
not get in the way of local public-  
private solutions nor should the state  
prohibit access to essential life  
supports for an individual to live in a  
home of their choosing.

*How can we fix it?*

The shortage of affordable housing, including permanent supportive housing (PSH), is the primary barrier to helping people with disabilities move from expensive institutions to the community and to ending homelessness. As documented in the forthcoming *Priced Out* in 2014, communities across the country face the same crisis.

*What can we do to end homelessness and provide people with disabilities opportunities to live integrated in their community?*

*At the National Level, use *Priced Out* data to:*

- Support efforts to fund the Section 811 PRA Program in every state;
- Support and protect efforts to fund the National Housing Trust Fund; and
- Advocate that National Housing Trust Fund funds be targeted to extremely low income (ELI) people with disabilities;
- Inform plans to end homelessness through Continuums of Care;
- Advocate for voucher and public housing preferences for people with disabilities in Public Housing Authority Plans;
- Advocate for targeting ELI people with disabilities in the state's Qualified Allocation Plan; and
- Demonstrate the need for housing for people with disabilities in state and local Consolidated Plans.



MADISON  
HOUSE  
AUTISM  
FOUNDATION



*In 2014, it was impossible for a single adult anywhere in the country receiving SSI to obtain decent and safe housing in the community unless they had some type of permanent rental subsidy.*

*What is *Priced Out*?*

Produced with the Consortium for Citizens with Disabilities with the support of the Mobilize Charitable Trust, *Priced Out* in 2014 is the 9th edition of the biennial national housing study documenting the severity of the housing affordability crisis experienced by the lowest-income people with disabilities. The Technical Assistance Collaborative, Inc. (TAC) is a national nonprofit organization that advances proven solutions to the housing and community support service needs of low-income people with disabilities and people who are homeless. This analysis is informed by data from HUD and the Social Security Administration as well as state level data reported on homelessness and institutionalization. See more at [www.tacinc.org](http://www.tacinc.org) or call (617) 457 ext. 119.

# Access to Housing: *Out of Reach 2015*



NATIONAL LOW INCOME  
HOUSING COALITION

BLOG TWITTER FACEBOOK LINKEDIN PRESS



Search



ABOUT  
US

POLICY  
FOCUS

TAKE  
ACTION

GET  
INVOLVED

EVENTS &  
TRAINING

RESOURCE  
LIBRARY

## Out of Reach 2015

About Out of Reach

Out of Reach in the News

[View State Data](#)

How Much do you Need to Earn to Afford a  
Modest Apartment [in Your State?](#)

Hourly wage required to rent a two bedroom unit by state.

Below \$15.00

\$15.00 - \$20.00

Above \$20.00



In order to afford housing,  
individuals with I/DD must  
work full-time for over double  
the minimum wage.

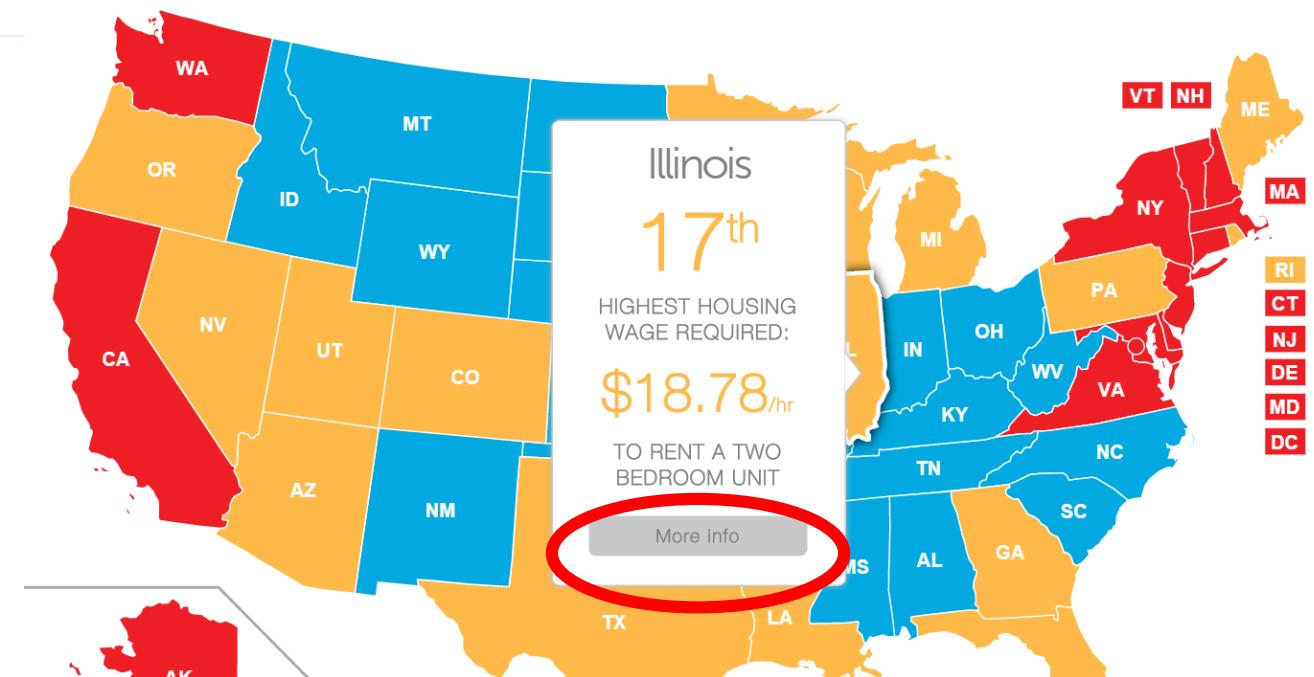
[National Low Income Housing Coalition](#) is NOT  
disability-specific, but shows the necessary  
income to afford housing across the country.

Hourly wage required to rent a two bedroom unit by state.

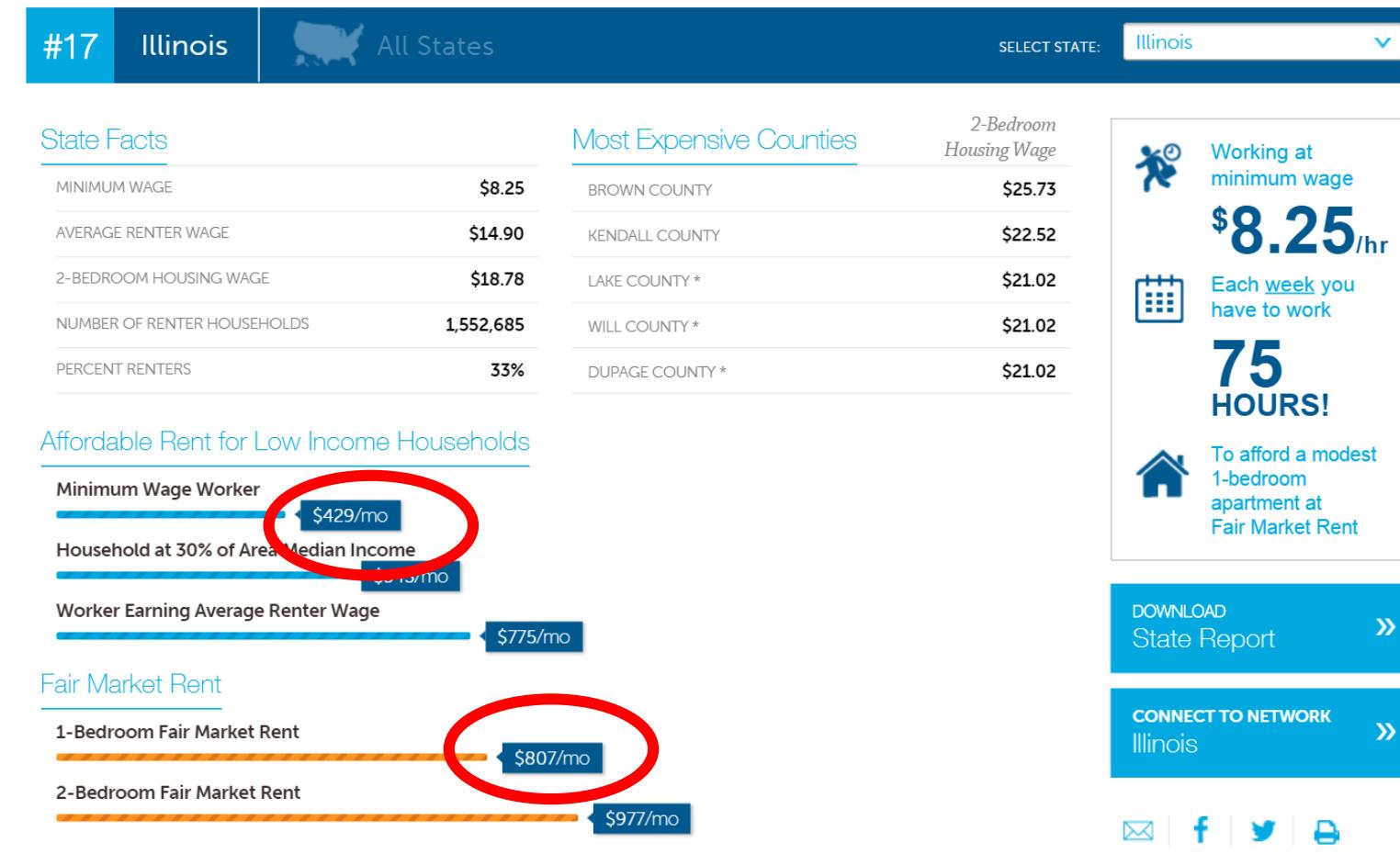
Below \$15.00

\$15.00 - \$20.00

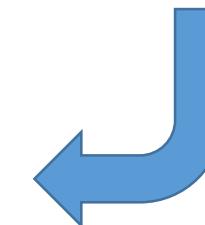
Above \$20.00



# Access to Housing: *Out of Reach 2015*



[Out of Reach State Profile](#) offers lots of information about housing affordability at the county level as well as the opportunity to connect with others in your state.



\$220 monthly rent would be considered 'affordable' for someone whose income is solely SSI in Illinois.

# Access to Housing: *Out of Reach 2015*

## Housing Wage

ZERO-BEDROOM

ONE-BEDROOM

TWO-BEDROOM

THREE-BEDROOM

FOUR-BEDROOM

	Illinois	Chicago-Naperville-Joliet HMFA *
ZERO-BEDROOM	\$13.52	\$15.62
ONE-BEDROOM	\$15.51	\$17.73
TWO-BEDROOM	\$18.78	\$21.02
THREE-BEDROOM	\$24.23	\$26.79
FOUR-BEDROOM	\$28.17	\$31.23

## Fair Market Rent

ZERO-BEDROOM

ONE-BEDROOM

TWO-BEDROOM

THREE-BEDROOM

FOUR-BEDROOM

	Illinois	Chicago-Naperville-Joliet HMFA *
ZERO-BEDROOM	\$703	\$812
ONE-BEDROOM	\$807	\$922
TWO-BEDROOM	\$977	\$1,093
THREE-BEDROOM	\$1,260	\$1,393
FOUR-BEDROOM	\$1,465	\$1,624

## Annual Income Needed to Afford

ZERO-BEDROOM

ONE-BEDROOM

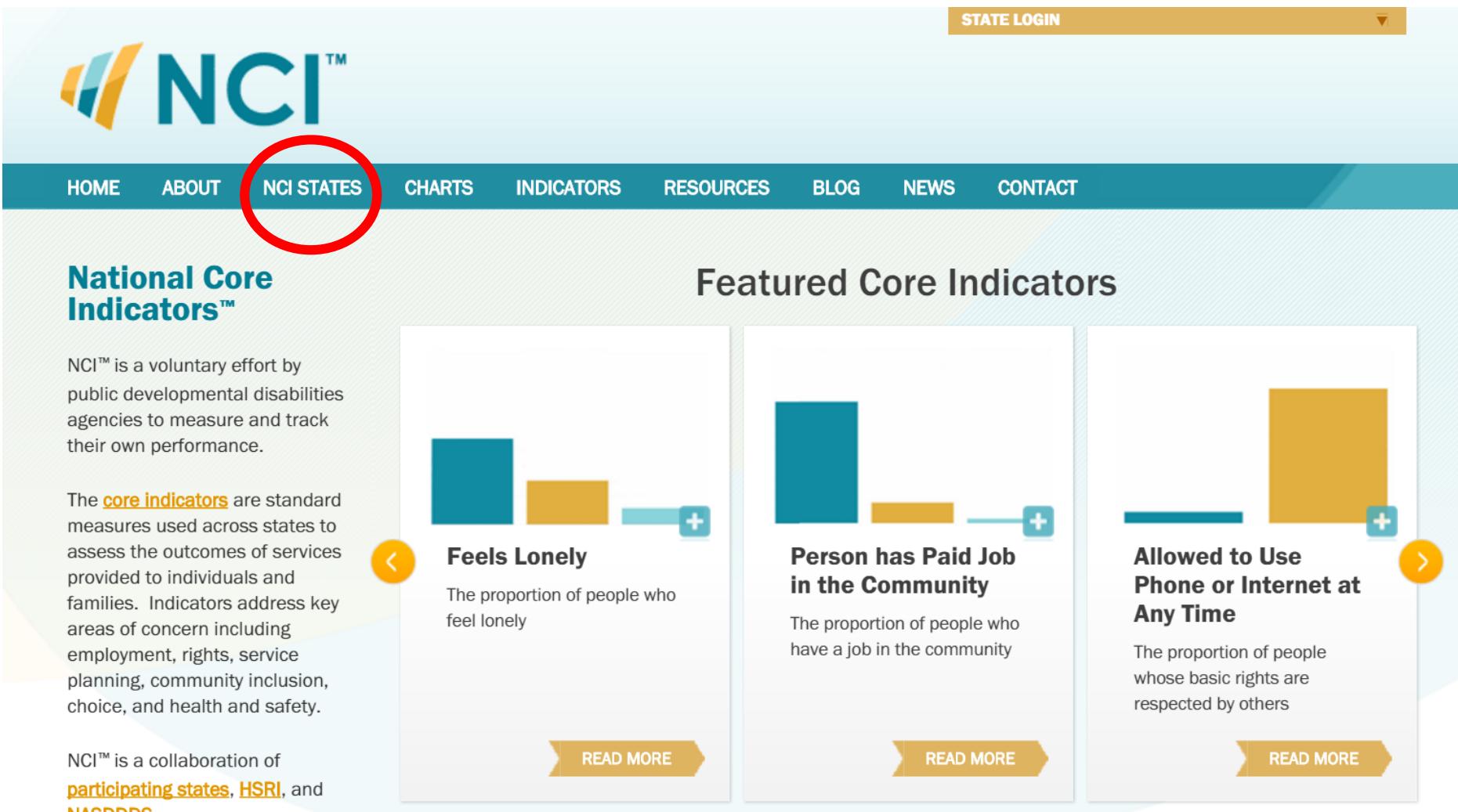
TWO-BEDROOM

THREE-BEDROOM

	Illinois	Chicago-Naperville-Joliet HMFA *
ZERO-BEDROOM	\$28,131	\$32,480
ONE-BEDROOM	\$32,260	\$36,880
TWO-BEDROOM	\$39,067	\$43,720
THREE-BEDROOM	\$50,391	\$55,720

**IMPORTANT QUESTION:**  
How can the state remove barriers and support local public-private initiatives that increase the affordable housing supply for those who never will earn an annual wage of \$30,000?

# Quality of Life: *National Core Indicators*



The screenshot shows the homepage of the National Core Indicators (NCI) website. The header features the NCI logo and a navigation bar with links for HOME, ABOUT, NCI STATES, CHARTS, INDICATORS, RESOURCES, BLOG, NEWS, and CONTACT. A red circle highlights the 'NCI STATES' link. The main content area is titled 'Featured Core Indicators' and displays three cards. Each card has a large colored square (teal, gold, and orange respectively), a title, a brief description, and a 'READ MORE' button. Navigation arrows are present between the cards.

**STATE LOGIN**

**NCI STATES**

**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**

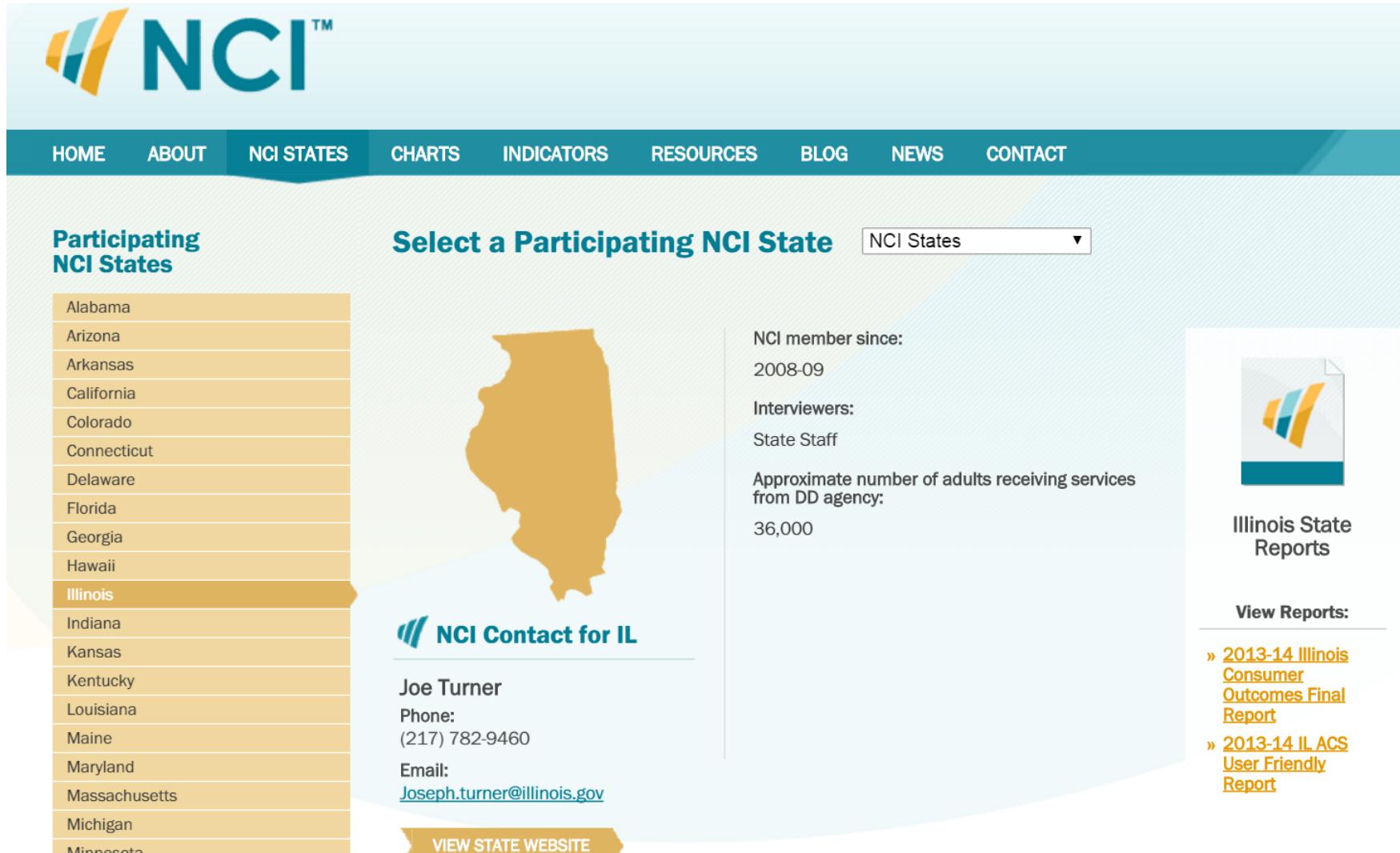
**Feels Lonely**  
The proportion of people who feel lonely

**Person has Paid Job in the Community**  
The proportion of people who have a job in the community

**Allowed to Use Phone or Internet at Any Time**  
The proportion of people whose basic rights are respected by others

National Core Indicators data is available in most states. It is being used in some states as part of their evaluation and assessment of quality of life of waiver participants during the period of State Transition.

# Quality of Life: *National Core Indicators*

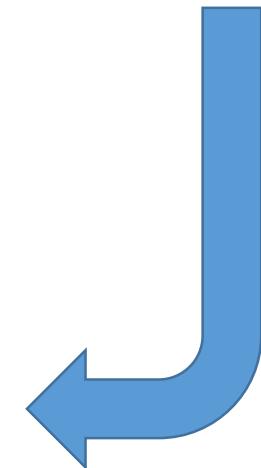


The screenshot shows the NCI website with the URL [www.nciweb.org/nci-states/illinois](http://www.nciweb.org/nci-states/illinois). The page title is "Select a Participating NCI State" and the dropdown menu shows "Illinois" is selected. The main content area displays information for Illinois, including:

- NCI member since: 2008-09
- Interviewers: State Staff
- Approximate number of adults receiving services from DD agency: 36,000

On the left, a sidebar lists "Participating NCI States" with Illinois highlighted. Below the list is a large orange silhouette of the state of Illinois. At the bottom of the page is a "VIEW STATE WEBSITE" button.

National Core Indicators data for most states can be downloaded as a PDF.



# Quality of Life: *National Core Indicators*

STATE LOGIN ▾

**NCI™**

HOME ABOUT NCI STATES CHARTS INDICATORS RESOURCES BLOG NEWS CONTACT

**National Core Indicators™**

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[CHART GENERATOR](#)

[INDICATOR INDEX](#)

## Featured Core Indicators

  
**Feels Lonely**  
The proportion of people who feel lonely

  
**Person has Paid Job in the Community**  
The proportion of people who have a job in the community

  
**Allowed to Use Phone or Internet at Any Time**  
The proportion of people whose basic rights are respected by others

[READ MORE](#) [READ MORE](#) [READ MORE](#)

National Core Indicators can generate state specific charts of data giving a snapshot of different aspects of quality of life.

For example: How much money are individuals making in community settings?

# Quality of Life: *National Core Indicators*

Learn how to use the NCI Chart Generator

**WATCH VIDEO**



## 1. Measure

If Self-Directing Needs Mo...

If Self-Directing Needs More Help Deciding How to Use Budget/Services

If Self-Directing Someone Talks About Budget/Services

If Self-Directing Support Workers Come When They are Supposed to

If Self-Directing Who Employs Support Workers?

Uses a Self-Directed Supports Option

## Work

Amount of Community Gross Wages Earned During Two-Week Period

Amount of Facility-Based Gross Wages Earned During Two-Week Period

Community Employment a Goal in Service Plan

Community Hourly Wage

Does Volunteer Work

Facility-Based Hourly Wage

Goes to Day Program or Does Other Activity During the Day

a chart.

**GENERATE CHART**



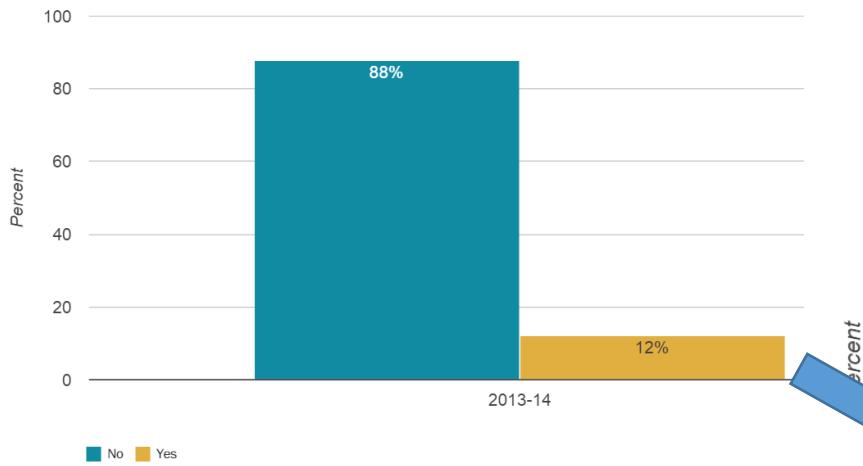
State(s): N/A

- 1) Select measure
- 2) Select State
- 3) Click gold generate chart button

# Quality of Life: *National Core Indicators*

## Person in Community Paid Job

The proportion of people who have a job in the community.

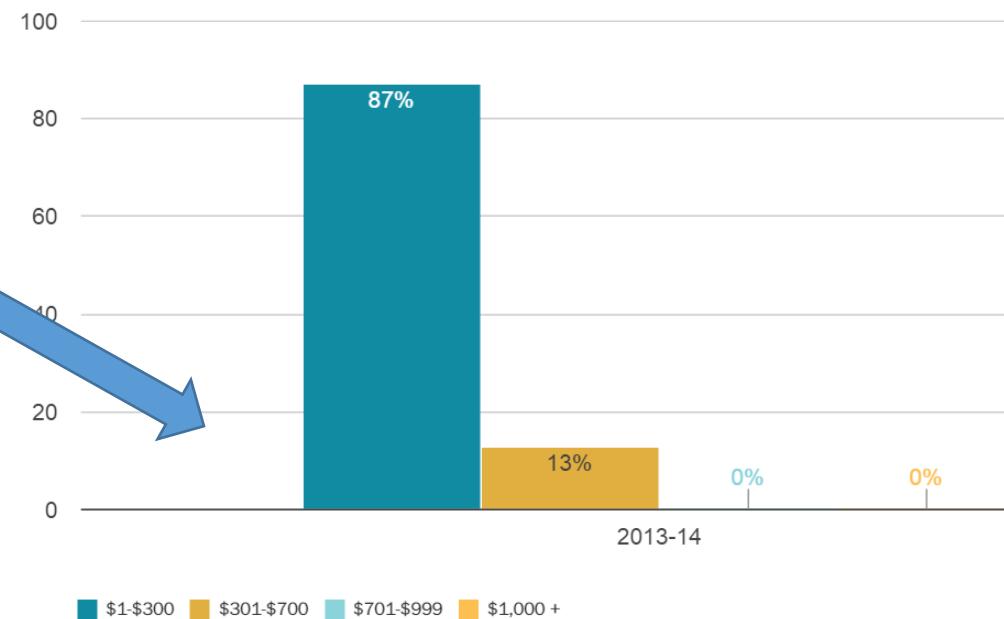


Total Respondents: 336

<a href="#">Cerebral Palsy 2013-14 and beyond</a>	<a href="#">Choose Roommates</a>	<a href="#">Last Pap Test Screening for Women 18 and Older</a>	<a href="#">Adaptations/Home Modifications</a>
<a href="#">Chemical Dependency</a>	<a href="#">Number of Community Jobs Visited</a>	<a href="#">Last Mammogram for Women Over 40</a>	<a href="#">If Does Not Get Needed Services Needs Health Care</a>
<a href="#">Chemical Dependency 2013-14 and beyond</a>	<a href="#">Number of Day Activities Visited</a>		<a href="#">If Does Not Get Needed Services Needs Help/Finding/Changing Housing</a>
<a href="#">Number of Homes Visited</a>			<a href="#">If Does Not Get Needed Services Needs Help/Finding/Changing Jobs</a>
<a href="#">Communication Disorder</a>			<a href="#">If Does Not Get Needed Services Needs Family Support</a>
<a href="#">Down Syndrome</a>	<a href="#">Community Inclusion</a>	<a href="#">Takes Medications for Anxiety</a>	<a href="#">If Does Not Get Needed Services Needs Service Coordination/Case Management</a>
<a href="#">Down Syndrome 2013-14 and beyond</a>	<a href="#">Amount of Times Went on Vacation in Past Year</a>	<a href="#">Takes Medications for Behavior Problems</a>	<a href="#">If Does Not Get Needed Services Needs Social/Relationships</a>
<a href="#">Ethnicity</a>	<a href="#">Amount of Times Went Out for Entertainment in Past Month</a>	<a href="#">Takes Medications for Mood Disorders</a>	<a href="#">If Does Not Get Needed Services Transportation</a>
<a href="#">Frequency of Medical Care</a>	<a href="#">Amount of Times Went Out for Exercise in Past Month</a>	<a href="#">Takes Medications for Psychotic Disorders</a>	
<a href="#">Frequency of Seizures</a>	<a href="#">Amount of Times Went Out on Errands/Appointments in Past Month</a>		
<a href="#">Gender</a>	<a href="#">Amount of Times Went Out To a Restaurant/Coffee Shop in Past Month</a>		
<a href="#">Hearing Loss: Severe or Profound</a>	<a href="#">Amount of Times Went Out To Religious Services in Past Month</a>	<a href="#">Respect/Rights</a>	<a href="#">Service Coordination</a>
<a href="#">Hearing Loss: Severe or Profound 2013-14 and beyond</a>	<a href="#">Amount of Times Went Shopping in Past Month</a>	<a href="#">Day Program/Other Activity Staff Nice</a>	<a href="#">Gets Help Needed to Work Out Problems with Support Workers</a>
<a href="#">Length of Time at Current Residence</a>	<a href="#">In the Past Month Person Went Out for Entertainment</a>	<a href="#">Home Staff Nice</a>	<a href="#">Support Workers Come When They are Supposed to</a>
<a href="#">Level of Intellectual Disability</a>	<a href="#">In the Past Month Person Went Out for Exercise</a>	<a href="#">Paid Community Job Staff Nice</a>	<a href="#">Case Manager/Service Coordinator Asks What They Want</a>
<a href="#">Limited or No Vision: Legally Blind</a>	<a href="#">In the Past Month Person Went Out on Errands/Appointments</a>	<a href="#">Support Staff Treats Person With Respect</a>	<a href="#">Case Manager/Service Coordinator Helps Get What They Need</a>
<a href="#">Limited or No Vision: Legally Blind 2013-14 and beyond</a>	<a href="#">In the Past Month Person Went Went to Work</a>	<a href="#">Participates in Self Advocacy Meetings</a>	<a href="#">Has Met Their Case Manager/Service Coordinator</a>
<a href="#">Marital Status</a>		<a href="#">Has Enough Privacy at Home</a>	
<a href="#">Mental Illness or Psychiatric Diagnosis</a>		<a href="#">Allowed to Use Phone or Internet at Any Time</a>	
<a href="#">Mental Illness or Psychiatric Diagnosis</a>		<a href="#">Can be Alone with Friends/Visitors when They Come to Visit</a>	
<a href="#">Mental Illness or Psychiatric Diagnosis</a>			

## **Amount of Community Gross Wages Earned During Two-Week Period**

The average bi-weekly earnings of people who have jobs in the community.



**Total Respondents: 30**

Less than 2% are making at least \$7,200 annually in paid community jobs in IL. Combined with SSI, this gives an annual income of less than \$16,000. Economic self-sustainability is not a realistic solution for most individuals with I/DD!



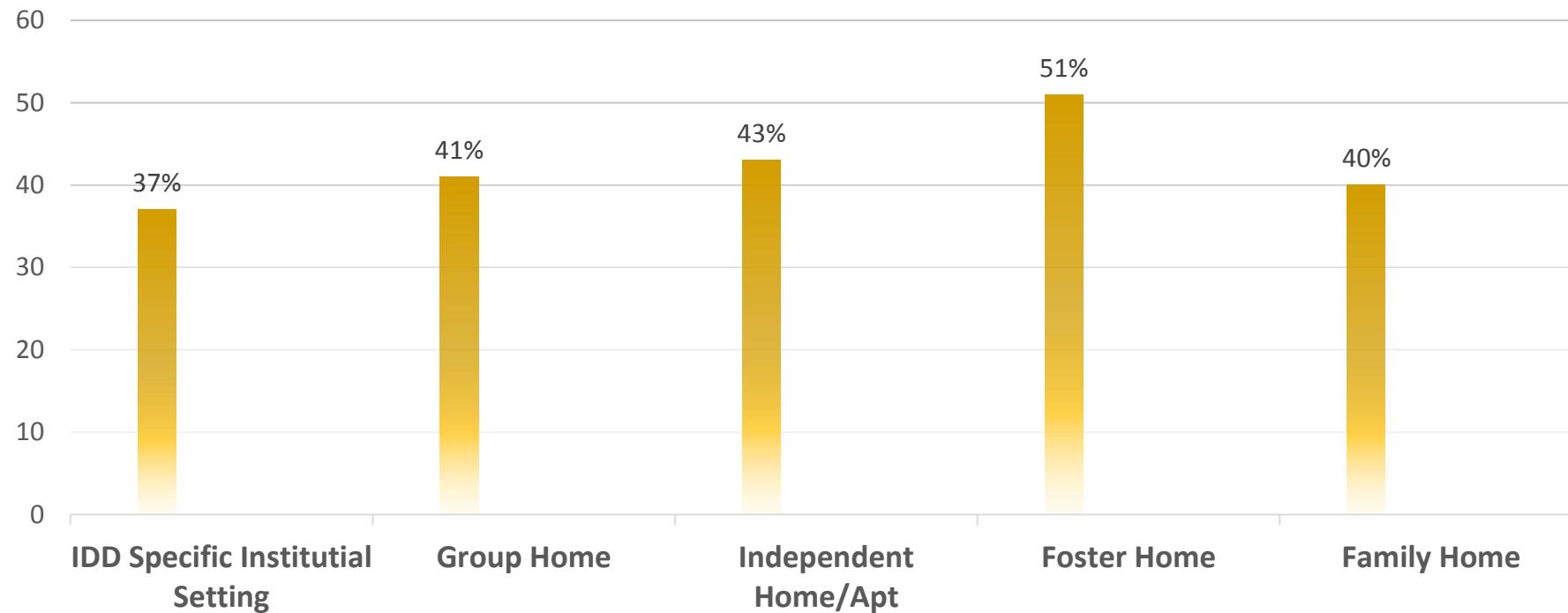
# Quality of Life: *National Core Indicators*

## 4. Filter

(0 of 2 selected)

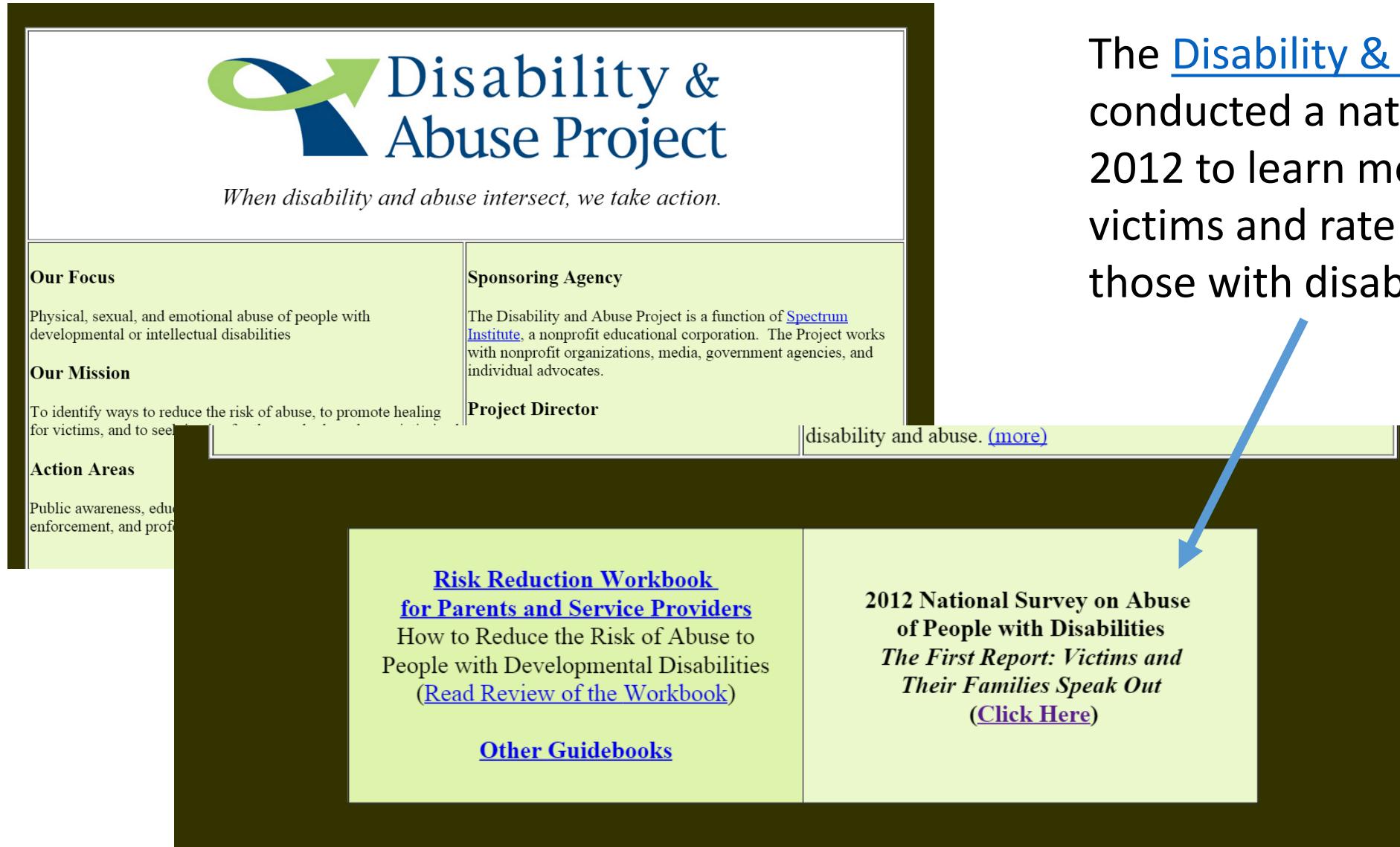
Level of ID	+
Type of Residence	+
Race	+
Ethnicity	+
Gender	+
Age	+
Mental Illness or Psychiatric Diagnosis	+
Autism	+
Primary Means of Expression	+

## INDV. WITH I/DD WHO 'SOMETIMES' OR 'OFTEN' FEEL LONELY BY SETTING (2012-2013)



IMPORTANT QUESTION: If individuals with I/DD feel the most lonely in a “home-like” foster setting or their own apartment- why are these settings given greater “home” value than IDD specific settings? Why are states using physical characteristic as HCB values instead of how many unpaid friendships people have?

# Abuse: Disability Abuse Project, 2012 National Survey



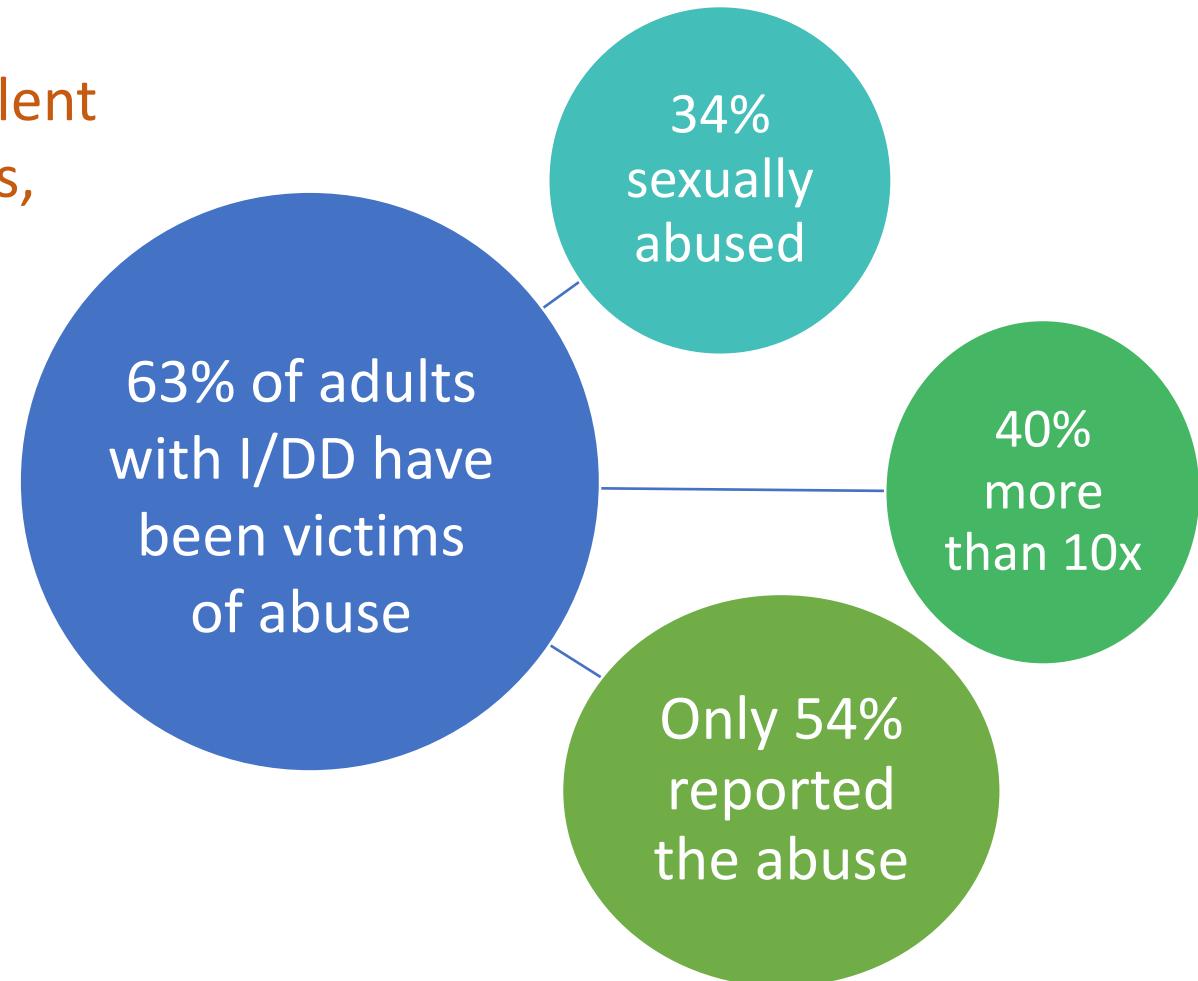
The screenshot shows the homepage of the Disability & Abuse Project. The header features a green and blue stylized arrow logo followed by the text "Disability & Abuse Project" and the tagline "When disability and abuse intersect, we take action." Below the header, there are four main sections: "Our Focus" (Physical, sexual, and emotional abuse of people with developmental or intellectual disabilities), "Our Mission" (To identify ways to reduce the risk of abuse, to promote healing for victims, and to see that justice is served), "Action Areas" (Public awareness, education, enforcement, and professional development), and "Sponsoring Agency" (The Disability and Abuse Project is a function of [Spectrum Institute](#), a nonprofit educational corporation. The Project works with nonprofit organizations, media, government agencies, and individual advocates). At the bottom, there are two call-to-action boxes: "Risk Reduction Workbook for Parents and Service Providers" (How to Reduce the Risk of Abuse to People with Developmental Disabilities, [\(Read Review of the Workbook\)](#)) and "2012 National Survey on Abuse of People with Disabilities" (The First Report: Victims and Their Families Speak Out, [\(Click Here\)](#)).

The Disability & Abuse Project conducted a national survey in 2012 to learn more about the victims and rate of abuse of those with disabilities.

# Abuse: Disability Abuse Project, 2012 National Survey

“The bottom line is that abuse is prevalent and pervasive, it happens in many ways, and it happens repeatedly to victims with all types of disabilities.”

Reasons for not reporting:		
58% believed nothing would happen	38% had been threatened or were afraid	33% did not know how or where to report



# Abuse: Disability Abuse Project, 2012 National Survey

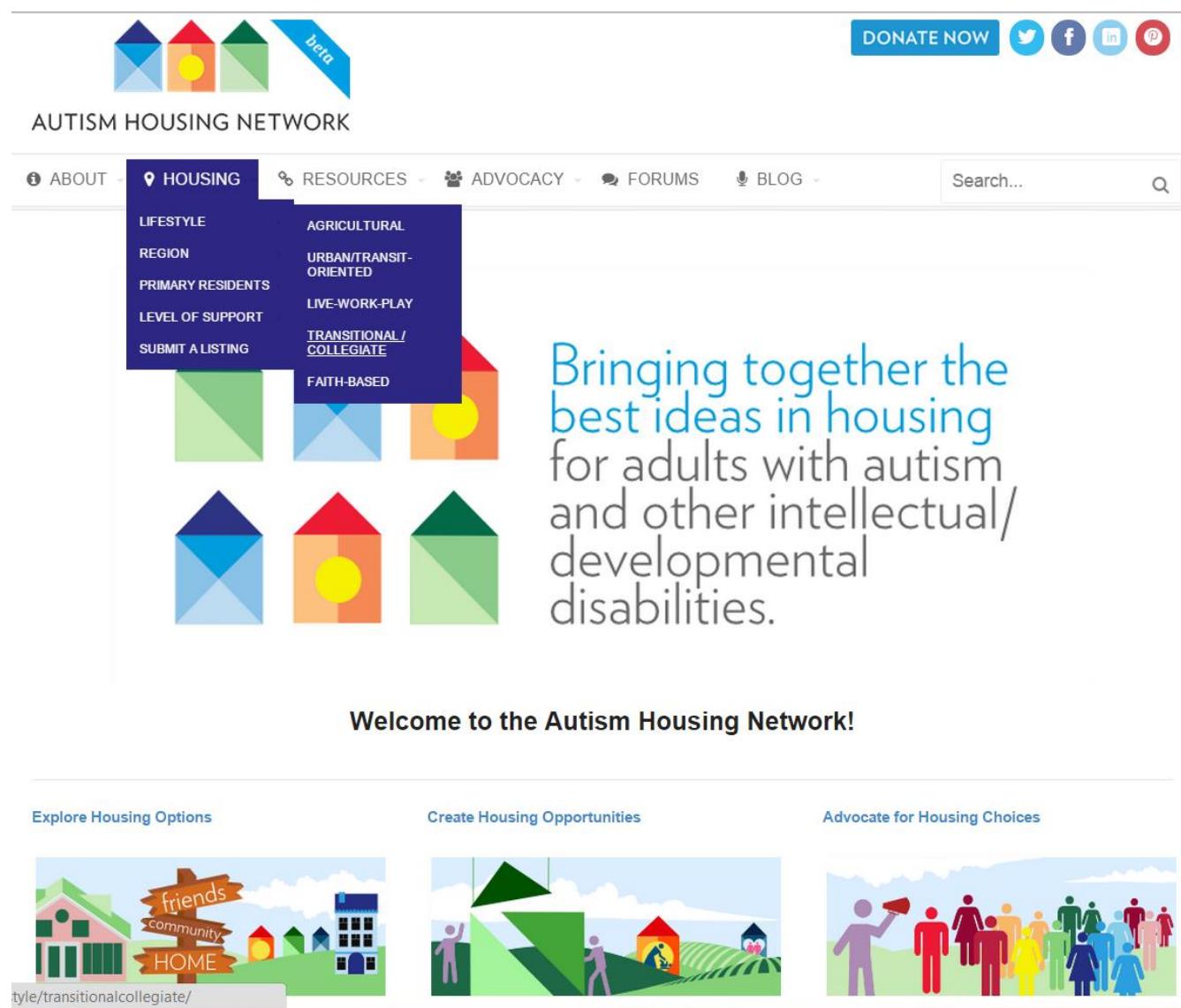
<a href="#">Dr. Nora's Blog</a>	<a href="#">Ten Tips to Reduce Risk</a>	<a href="#">Make a Donation</a>
<a href="#">What's New</a> <a href="#">News Feed</a> <a href="#">Listserv</a> <a href="#">Executive Committee</a>	<a href="#">Project Consultants</a> <a href="#">Data, Research, Reports</a> <a href="#">Tributes and Proclamations</a> <a href="#">Resources / Books</a>	<a href="#">Contact Us</a>  <a href="#">Log In</a> To use Facebook's social plugins, you must switch from using Facebook as Coalition for <a href="#">Siree' Kameka</a> .
<a href="#">Project Archives</a>	<h2>Abuse Project</h2> <p><i>When disability and abuse intersect, we take action.</i></p> <p><b>Newsfeed on Disability and Abuse</b> Prepared by Anne M. Kincaid</p> <p>The Disability and Abuse Project of Spectrum Institute supports this newsfeed. Articles are of interest to individuals with disabilities and those supporting and working with and for individuals with disabilities.</p> <p>These are articles involving people with disabilities across the life span, any type of disability and any type of maltreatment, abuse, or crime or articles regarding law enforcement issues and individuals with disabilities. We have a particular focus on individuals with developmental disabilities. We welcome your input and feedback about this service.</p> <p>Please note that the articles are listed in alphabetical order by State, so you can easily scan through the articles for those within your state or other states in which you have a particular interest.</p> <p><b>Current News</b> <a href="#">September 14, 2015</a></p> <p><b>Archives</b> <a href="#">September 7, 2015</a></p>	

[The Project 'newsfeed'](#) archives compiled lists of abuse cases that have been in the media since 2011. Look for your state in CAPS.

**Abuse/Crime-related**

1. "Family Seeking Answers on Autistic Son's Head Injury" --- A Tuscaloosa family gets a frantic call that their autistic son, they entrusted in the care of others is in the hospital with a severe head injury. No one can ... --- WAFF --- September 10, 2015 (ALABAMA) <http://is.gd/jk4PGI>
2. "Caretaker's Trial Set in Disabled Man's Death" --- A November trial date has been set for a man accused of allowing a mentally handicapped man in his care to die, then dumping his ... --- Arkansas Online --- September 11, 2015 (ARKANSAS) <http://is.gd/nUiFyt>
3. "California Special Needs Teen Found Dead on School Bus" --- California police are investigating after a 19-year-old special needs student was found dead in a school bus. --- [WAFB.com](#) --- September 12, 2015 (CALIFORNIA) <http://is.gd/EogZEh>
4. "Disabled Man Tells Anaheim Police Robbers Bound Him with Duct Tape, Stole Large Amount of Cash ..." --- A disabled man was found in his home bound with duct tape by a neighbor Wednesday night after he was apparently robbed by at ... --- OCRegister --- September 10, 2015 (CALIFORNIA) <http://is.gd/5a51Tx>

# Working together, we *CAN* make a difference!



The screenshot shows the homepage of the Autism Housing Network. At the top, there is a navigation bar with a logo of colorful stylized houses, a "DONATE NOW" button, and social media links for Twitter, Facebook, LinkedIn, and Pinterest. Below the navigation is a search bar. The main content area features a large image of colorful houses and the text: "Bringing together the best ideas in housing for adults with autism and other intellectual/developmental disabilities." Below this, a welcome message reads: "Welcome to the Autism Housing Network!" At the bottom, there are three calls to action: "Explore Housing Options", "Create Housing Opportunities", and "Advocate for Housing Choices", each accompanied by a small icon.

AUTISM HOUSING NETWORK

DONATE NOW

beta

ABOUT

HOUSING

RESOURCES

ADVOCACY

FORUMS

BLOG

Search...

LIFESTYLE

AGRICULTURAL

REGION

URBAN/TRANSIT-ORIENTED

PRIMARY RESIDENTS

LIVE-WORK-PLAY

LEVEL OF SUPPORT

TRANSITIONAL/COLLEGIATE

SUBMIT A LISTING

FAITH-BASED

Bringing together the best ideas in housing for adults with autism and other intellectual/developmental disabilities.

Welcome to the Autism Housing Network!

Explore Housing Options

Create Housing Opportunities

Advocate for Housing Choices



The Coalition for Community Choice (CCC) logo consists of three stylized green houses with the letters "CCC" inside. Below the logo, the text "Coalition for Community Choice" is displayed.

CCC

Coalition for Community Choice

The CCC is a new alliance of organizations, businesses, and housing professionals that strive to meet the housing and employment demand for an array of life options for those with intellectual/developmental disabilities (I/DD).



# For More Information:

[www.MadisonHouseAutism.org](http://www.MadisonHouseAutism.org)

[www.CoalitionForCommunityChoice.org](http://www.CoalitionForCommunityChoice.org)

[www.AutismHousingNetwork.org](http://www.AutismHousingNetwork.org)

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# What is the History of the Final Rule?

In response to Affordable Care Act, federal HCBS regulations needed to be revised:

2008: NPRM for 1915(i) - not finalized

2009: NPRM for 1915(c)

2011: NPRM for 1915(c)

2011: NPRM for 1915(k)

2012: NPRM for 1915(i) and 1915(k)

2013: NPRM for 1915(c), (i), and (k)

2014: [CMS-2249-F/CMS-2296-F published](#)

*"The Rule, as part of the Affordable Care Act, supports the Dept. of HHS Community Living Initiative. The initiative launched in 2009 to develop and implement innovative strategies to increase opportunities for Americans with disabilities and older adults to enjoy meaningful community living."*

*-CMS website*



# What's in the Final Rule?

- New regulations and criteria for residential and non-residential settings that use HCBS funding
- Settings eligibility based on individual outcomes and experiences
- Emphasis on integration in, and full access to, community same as those who are not receiving waiver services
- No setting size, physical characteristics, prohibition of disability-specific person limits
- Emphasized authority of and mandates Person Centered Plans to be created and reviewed in order to access funds
- Ensuring transparency and accountability via public comment periods
- Set a baseline, but gave states the flexibility to implement more restrictive regulations

# Final Rule and All HCBS Settings

- The setting is integrated in and supports full access of individuals receiving Medicaid HCBS to the greater community, including opportunities to seek employment and work in competitive integrated settings, engage in community life, control personal resources, and receive services in the community, to the same degree of access as individuals not receiving Medicaid HCBS.
- The setting is selected by the individual from among setting options including non-disability specific settings and an option for a private unit in a residential setting. The setting options are identified and documented in the person-centered service plan and are based on the individual's needs, preferences, and, for residential settings, resources available for room and board.

# Final Rule and All HCBS Settings

- Ensures an individual's rights of privacy, dignity and respect, and freedom from coercion and restraint.
- Optimizes, but does not regiment, individual initiative, autonomy, and independence in making life choices, including but not limited to, daily activities, physical environment, and with whom to interact.
- Facilitates individual choice regarding services and supports, and who provides them.

# Provider Owned or Controlled Settings

## ADDITIONAL criteria for provider owned or controlled settings:

- The unit or dwelling is a specific physical place that can be owned, rented, or occupied under a legally enforceable agreement by the individual receiving services, and the individual has, at a minimum, the same responsibilities and protections from eviction that tenants have under the landlord/tenant law of the State, county, city, or other designated entity. For settings in which landlord tenant laws do not apply, the State must ensure that a lease, residency agreement or other form of written agreement will be in place for each HCBS participant, and that the document provides protections that address eviction processes and appeals comparable to those provided under the jurisdiction's landlord tenant law.

# Provider Owned or Controlled Settings

- Each individual has privacy in their sleeping or living unit:
  - Units have entrance doors lockable by the individual, with only appropriate staff having keys to doors.
  - Individuals sharing units have a choice of roommates in that setting.
  - Individuals have the freedom to furnish and decorate their sleeping or living units within the lease or other agreement.
- Individuals have the freedom and support to control their own schedules and activities, and have access to food at any time.
- Individuals are able to have visitors of their choosing at any time.
- The setting is physically accessible to the individual.

# Exceptions to the Requirements

- Any modification must be supported by a specific assessed need and justified in the person-centered service plan:
  - Identify a specific and individualized assessed need.
  - Document the positive interventions and supports used prior to any modifications to the person-centered service plan.
  - Document less intrusive methods of meeting the need that have been tried but did not work.
  - Include a clear description of the condition that is directly proportionate to the specific assessed need.
  - Include regular collection and review of data to measure the ongoing effectiveness of the modification.
  - Include established time limits for periodic reviews to determine if the modification is still necessary or can be terminated.
  - Include the informed consent of the individual.
  - Include an assurance that interventions and supports will cause no harm to the individual.

# Settings NOT Eligible for HCBS Funding

- Settings that are not home and community-based are defined at §441.301(c)(5) as follows:
  - A nursing facility;
  - An institution for mental diseases;
  - An intermediate care facility for individuals with intellectual disabilities;
  - A hospital; or
  - Any other locations that have qualities of an institutional setting, as determined by the Secretary.

**\*These are the only settings explicitly stated in the Final Rule as NOT Home and Community-Based!**

# Settings PRESUMED NOT Eligible

- The following settings are presumed to have the qualities of an institution:
  - any setting that is located in a building that is also a publicly or privately operated facility that provides inpatient institutional treatment,
  - any setting that is located in a building on the grounds of, or immediately adjacent to, a public institution, or
  - any other setting that has the effect of isolating individuals receiving Medicaid HCBS from the broader community of individuals not receiving Medicaid HCBS.

\*These are PRESUMED to be institutional thus MAY need to undergo the heightened scrutiny process as determined by the State.

# Heightened Scrutiny & North Dakota

- First case of a setting presumed to be institutional: [Life Skills & Training Center, Grafton, ND](#)
- CMS contractor NORC conducted review
- Information provided by State and other parties
- Determine that it does not have qualities of an institution  
*and*
- Does have the qualities of HCBS

CMS determined LSTC meets HCBS setting criteria based on access to and integration of residents in community.

# CMS Guidance

- [CMS Guidance](#) expanded on the Final Rule and identified settings that are presumed to be institutional
- Settings that have these two characteristics alone might, but will not necessarily, meet the criteria for having the effect of isolating individuals:
  - #1 – The setting is designed specifically for people with disabilities, and often even for people with a certain type of disability
  - #2 – The individuals in the setting are primarily or exclusively people with disabilities and on-site staff provides many services to them.

# Guidance

- Settings that isolate people receiving HCBS from the broader community may have *any* of the following characteristics:
  - The setting is designed to provide people with disabilities multiple types of services and activities on-site, including housing, day services, medical, behavioral and therapeutic services, and/or social and recreational activities:
  - People in the setting have limited, if any, interaction with the broader community
  - Settings that use/authorize interventions/restrictions that are used in institutional settings or are deemed unacceptable in Medicaid institutional settings (e.g. seclusion)
- Non-exhaustive list of examples of residential settings that *typically* have the effect of isolating people receiving HCBS from the broader community:
  - Farmstead or disability-specific farm community
  - Gated/secured “community” for people with disabilities
  - Residential schools
  - Multiple settings co-located and operationally related (i.e. operated and controlled by the same provider)
    - -- Excluded CCRCs (Continuing Care Retirement Communities)

# Implementation Timeline

Jan. 10, 2014 - Final Rule published

March 17, 2014 - Transition Clock Starts

March 17, 2015 - State Transition Plans Due

March 17, 2019 - Transition Complete, All Settings Must  
be in Compliance

# CCC STP Concerns

CCC letter to CMS cited concerns:

- States were reverting back to physical characteristics instead of outcome oriented criteria
- States were telling advocates and providers that campus settings, farmsteads, and intentional communities would not be funded by CMS
- States were creating restrictive criteria that would automatically exclude settings from being evaluated or put through the higher scrutiny process

# Next Steps

Use the [CCC STP Mini-Toolkit](#) to learn more about the Final Rule and how to access and become part of your State Transition Plan process!

It is IMPERATIVE your voice is present, and the Final Rule requires that the state documents that they have heard your concerns and suggestions.

# Next Steps

- State will seek input for assessment tool for setting assessments.
  - Read and give feedback.
  - Remove questions that are based on physical characteristics.
  - Add questions that will identify and document barriers to access

*Example:*

- How many times a month does Maria go out to dinner?
- How many times does she want to go out to dinner?
- What prevents her from going out to dinner as often as she would like?

# Next Steps

- See if your state has created a transition advisory committee / workgroup and ask to join!

Stakeholders should include:

- HCBS recipients who reside in different settings
- Parents of HCBS recipients
- Service Providers
- Direct Support Professionals
- Affordable Housing Developers

- If none exist, request to create one.

# Next Steps

- Build relationships with your legislatures!
- They MUST become more aware of the statistics and stories of their constituents with I/DD who are struggling to be supported in their community and find appropriate affordable housing options.

# Next Steps

# Start the Person Centered Planning Process!

- Look at the Final Rule Requirements for PCP's
- Increase self-advocacy skills of HCBS recipients so they can lead the process as much as possible

