



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*



Prepared and presented by Desiree Kameka
*Director of Community Education & Advocacy, MHAF
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.

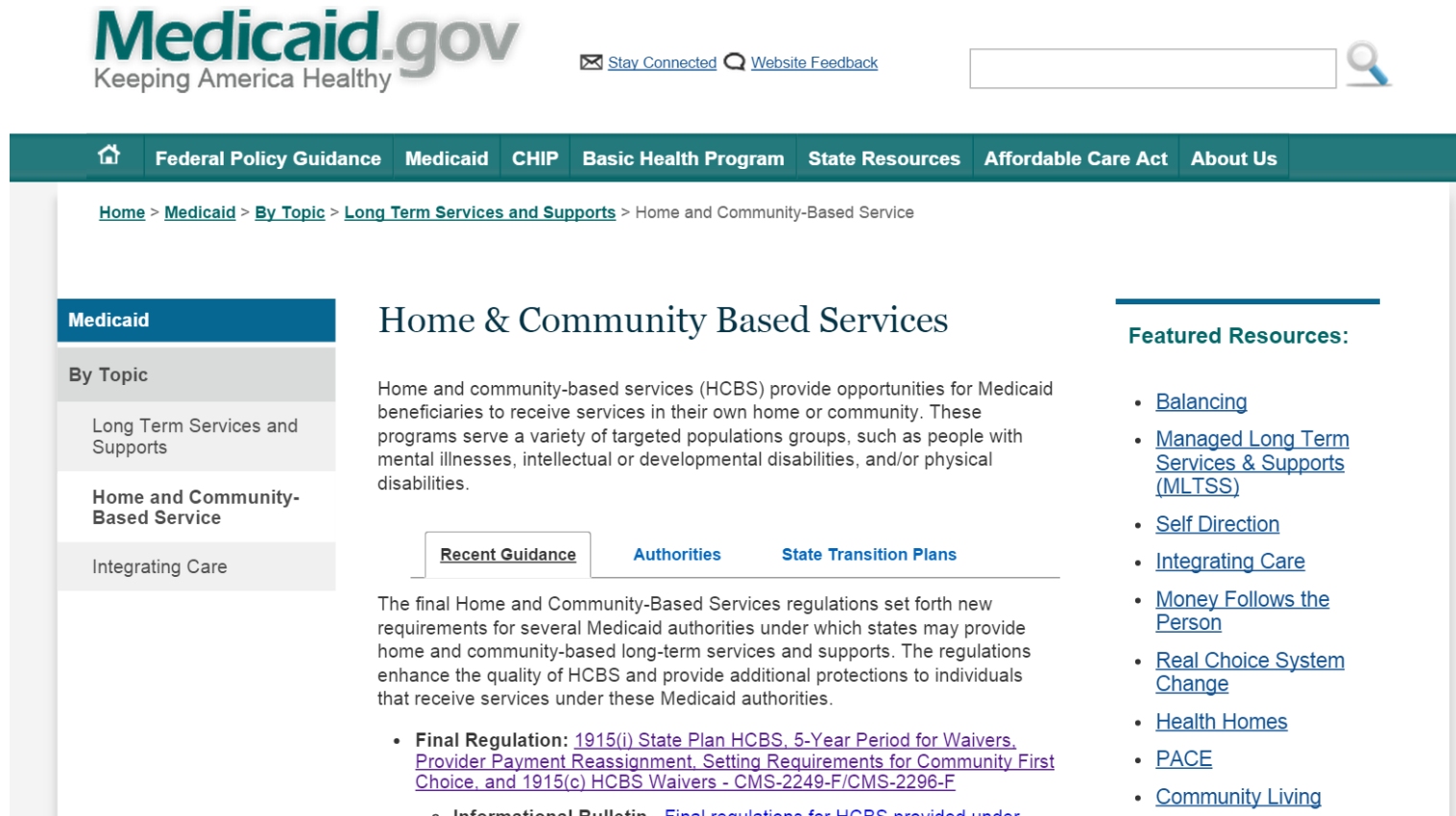


History of Policy Changes Supporting Choice

- 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 website. The header includes the Medicaid.gov logo with the tagline 'Keeping America Healthy', a 'Stay Connected' link, a 'Website Feedback' link, and a search bar. The navigation bar contains links for Home, Federal Policy Guidance, Medicaid, CHIP, Basic Health Program, State Resources, Affordable Care Act, and About Us. The breadcrumb trail reads: Home > Medicaid > By Topic > Long Term Services and Supports > Home and Community-Based Service. The left sidebar has a 'Medicaid' section with 'By Topic' including 'Long Term Services and Supports', 'Home and Community-Based Service', and 'Integrating Care'. The main content area is titled 'Home & Community Based Services' and includes a paragraph about HCBS, tabs for 'Recent Guidance', 'Authorities', and 'State Transition Plans', and a list of resources. The right sidebar is titled 'Featured Resources:' and lists several links.

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

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.

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](#)

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
<p>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.</p> <ul style="list-style-type: none">• 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<ul style="list-style-type: none">◦ 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<ul style="list-style-type: none">▪ 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.

CMS email for
questions and
concerns



Coalition for Community Choice

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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HCBS.
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"

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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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.



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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 > [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

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.

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

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](#)
- [Integrating Care](#)
- [Money Follows the Person](#)
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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 ¹	CMIA ²	Initial Approval ³	Final Approval ⁴	Approved Plan ⁵
Alabama	Available	Available 			
Alaska	Available 	Available 			
Arizona					
Arkansas	Available	Available 			
California	Available				
Colorado	Available	Available 			
Connecticut	Available	Available 			
Delaware	Available 	Available 			
District of Columbia	Available 	Available 			
Florida	Available	Available 			

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 needs and experiences of individuals with disabilities receiving them. The burden now remains on States, with CMS to demonstrate that housing, employment, and support service settings are compliant with the regulations. The need is significant.

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

FINAL RULE RELEASED

In January 2014, the Center for Medicare & Medicaid 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 find the **Final Rule** in the Federal Register.
- The Final Rule was developed to significantly improve the individualized supports and help the support service system become more person centered with fewer conflicts of interest. Characteristics of home and 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 of their citizens with IDD.
- 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



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](#)

Frequently Asked Questions About the New HCBS Regulations

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
- Demonstrate inaccess to affordable housing for those with I/DD in your state
- Explore quality of life assessments for those with I/DD in your state
- Demonstrate abuse is occurring “in community” and offer reports of victims 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

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STATE OF THE STATES IN DEVELOPMENTAL DISABILITIES

Welcome

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.

What's New

- 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](#)



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



The State of the States in Developmental Disabilities

University of Colorado

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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 ▼

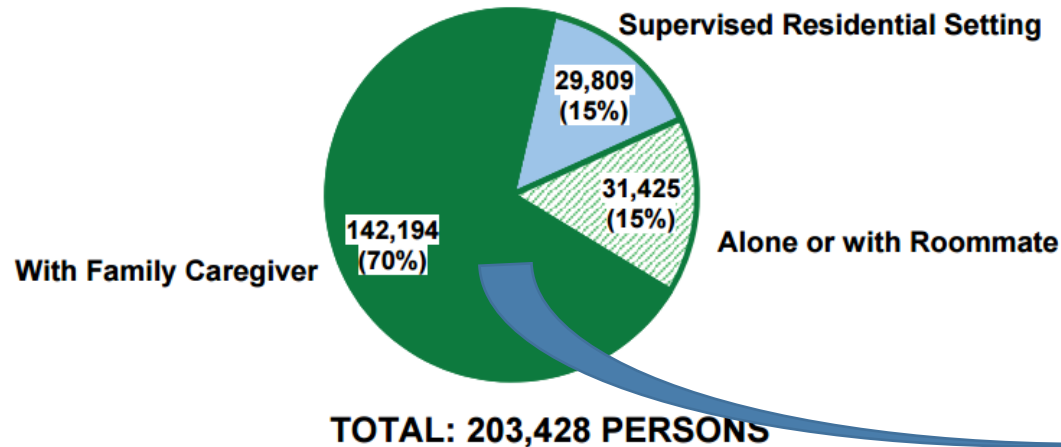
[View the United States profile](#)

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

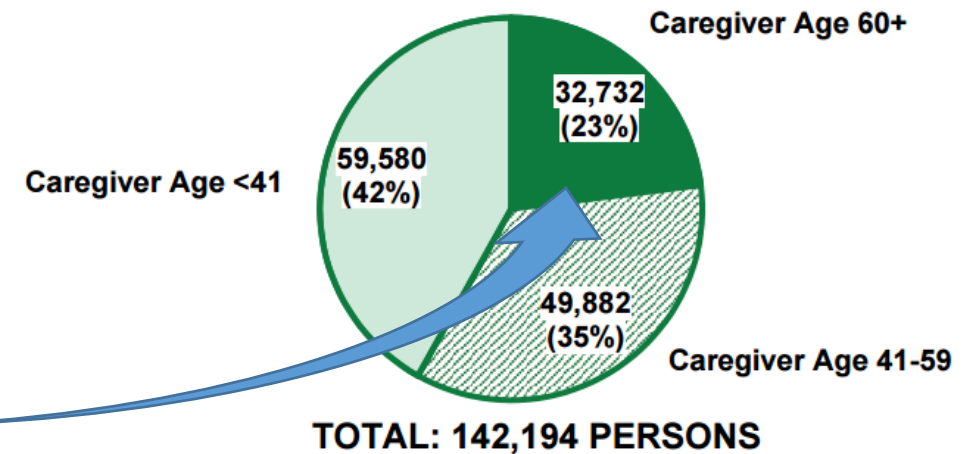
LTSS Supply & Demand: State of the States in I/DD 2015 Report

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



Braddock et al. 2014, based on Fujiura 2008, 2012

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

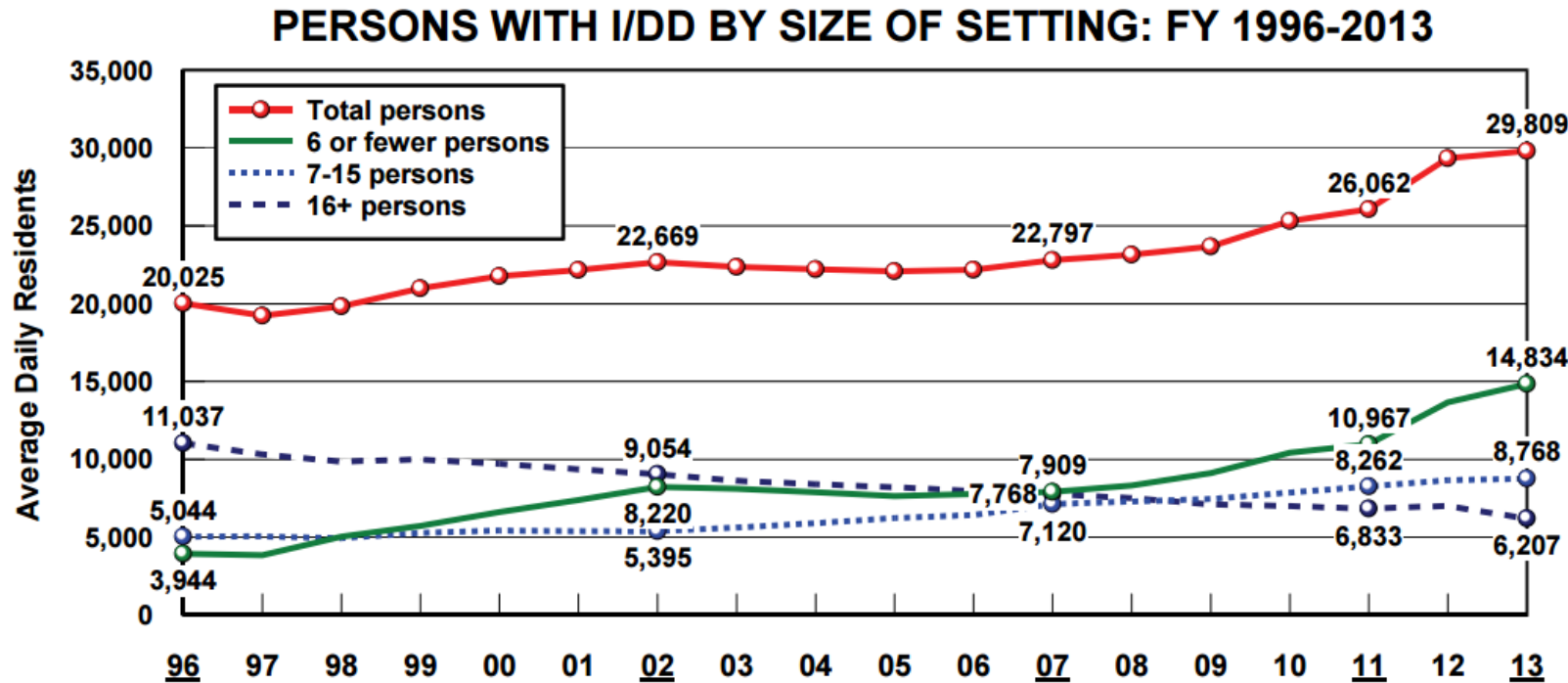


Braddock et al. 2014, based on Fujiura 2008, 2012

[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**

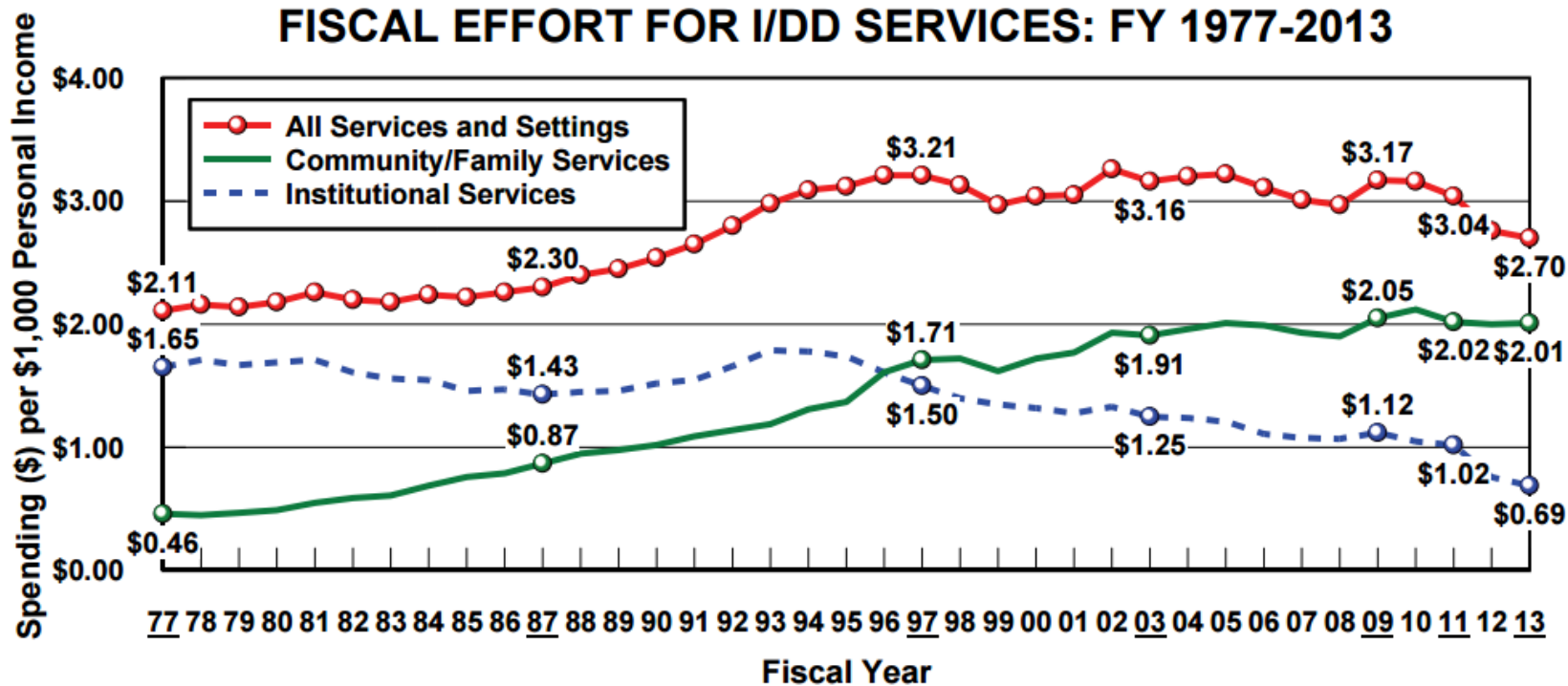
LTSS Supply & Demand: State of the States in I/DD 2015 Report



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

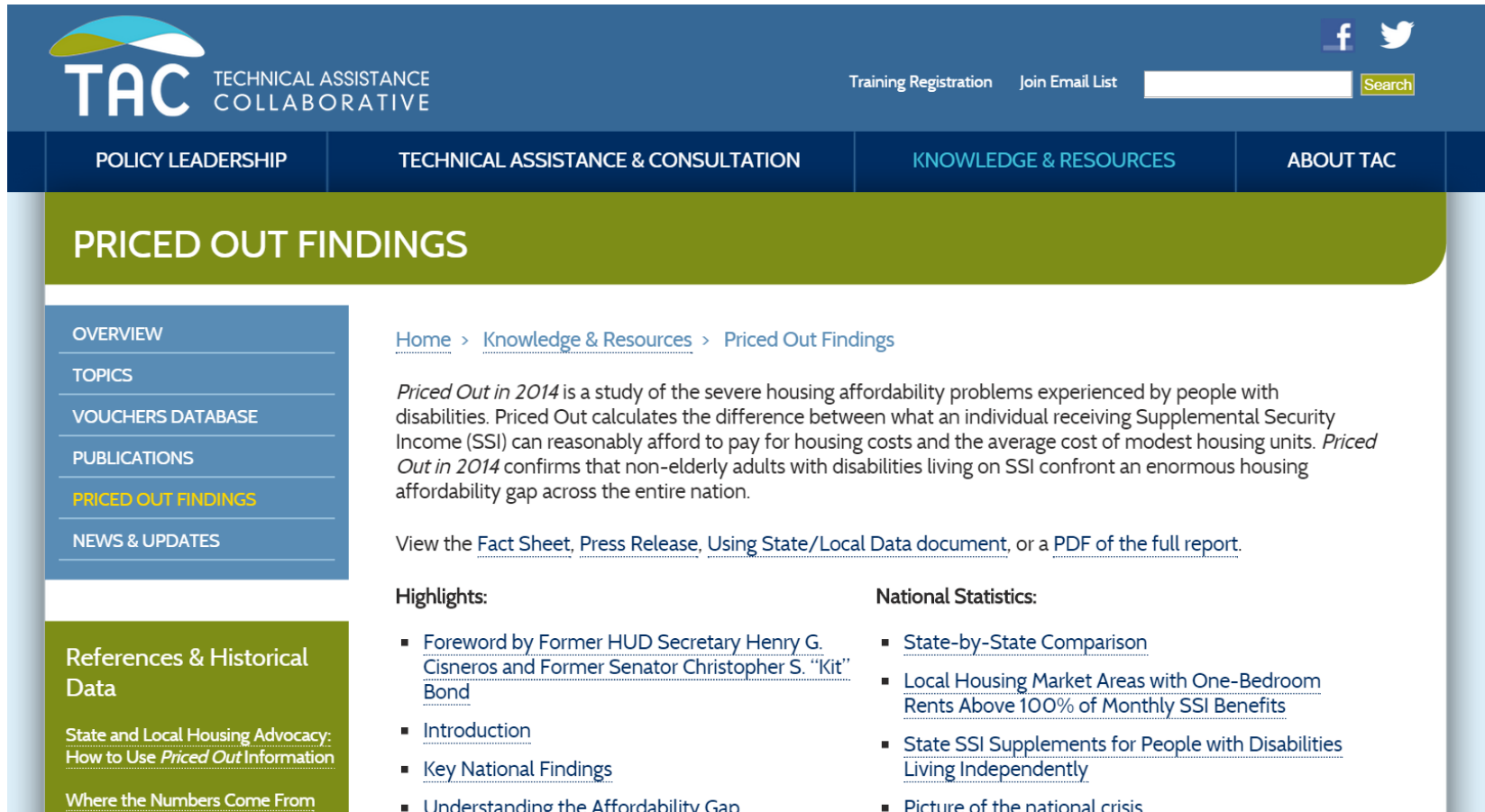


Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2014.

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 TAC Technical Assistance Collaborative website. The header includes the TAC logo, navigation links for Training Registration and Join Email List, and a search bar. The main navigation bar has four categories: POLICY LEADERSHIP, TECHNICAL ASSISTANCE & CONSULTATION, KNOWLEDGE & RESOURCES (highlighted), and ABOUT TAC. Below this, a green banner reads 'PRICED OUT FINDINGS'. A left sidebar lists various topics, with 'PRICED OUT FINDINGS' highlighted in yellow. The main content area features a breadcrumb trail (Home > Knowledge & Resources > Priced Out Findings), a paragraph describing the 'Priced Out in 2014' study, and links to view the Fact Sheet, Press Release, Using State/Local Data document, or a PDF of the full report. Two columns of links are provided: 'Highlights' (Foreword by Former HUD Secretary Henry G. Cisneros and Former Senator Christopher S. 'Kit' Bond, Introduction, Key National Findings, Understanding the Affordability Gap) and '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). A bottom sidebar titled 'References & Historical Data' includes links for 'State and Local Housing Advocacy: How to Use Priced Out Information' and 'Where the Numbers Come From'.

TAC TECHNICAL ASSISTANCE COLLABORATIVE

Training Registration Join Email List Search

POLICY LEADERSHIP TECHNICAL ASSISTANCE & CONSULTATION **KNOWLEDGE & RESOURCES** ABOUT TAC

PRICED OUT FINDINGS

OVERVIEW
TOPICS
VOUCHERS DATABASE
PUBLICATIONS
PRICED OUT FINDINGS
NEWS & UPDATES

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

References & Historical Data

[State and Local Housing Advocacy: How to Use *Priced Out* Information](#)

[Where the Numbers Come From](#)

- [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*

- 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?

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)

Highlights:

- 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:

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- Picture of the national crisis

2014 Illinois CHICAGO/JOLIET/NAPERVILLE

YEAR STATE MSA OR AREA (OPTIONAL)

[Submit](#)

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

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

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 State and Local level, use Priced Out data to:**
- Work with your state to apply for Section 811 Project Rental Assistance (PRA) funds;
 - 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.

- 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
 - Support the President's Fiscal Year 2016 HUD Budget Request, which restores 67,000 vouchers, provides for new funding for Section 811 PRA and increases PSH resources to end homelessness.

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 Melville 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 services 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 or call (617) 5457 ext. 119.

This is not affordable

See *Priced Out 2014* at www.tacinc.org to learn more about these alarming statistics



Fc
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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



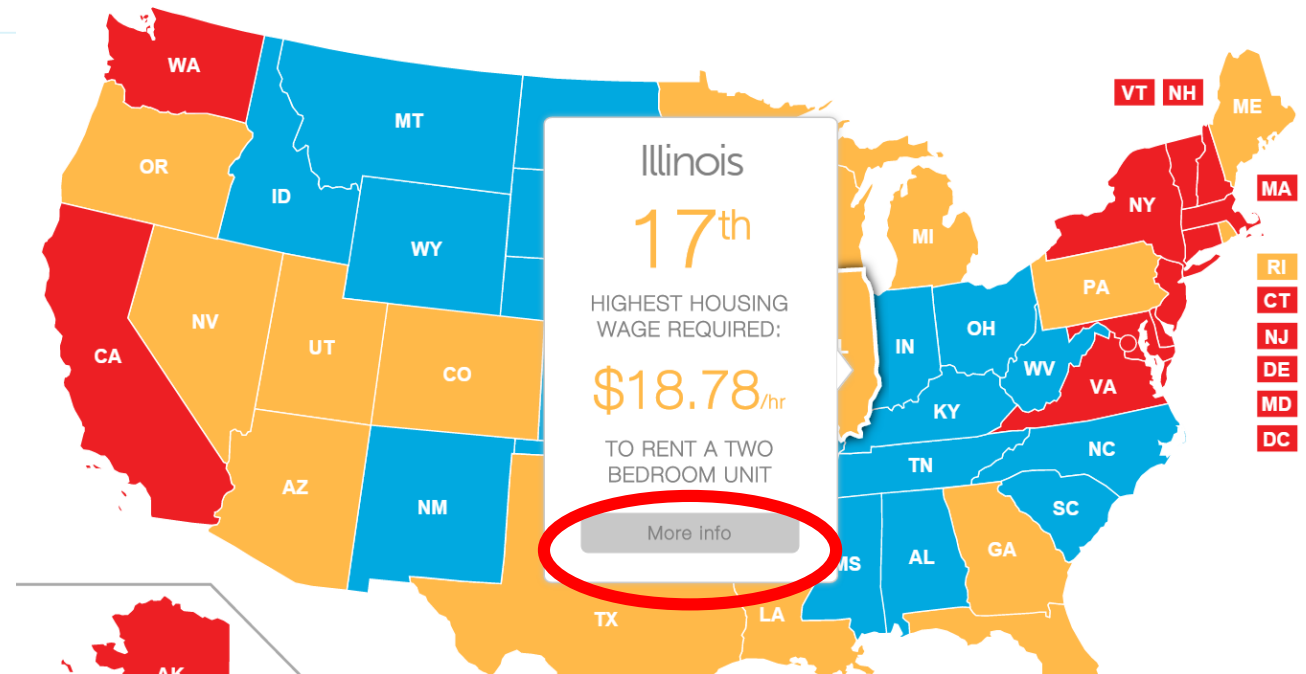
In order to afford housing,
individuals with I/DD must
work full-time for over double
the minimum wage.



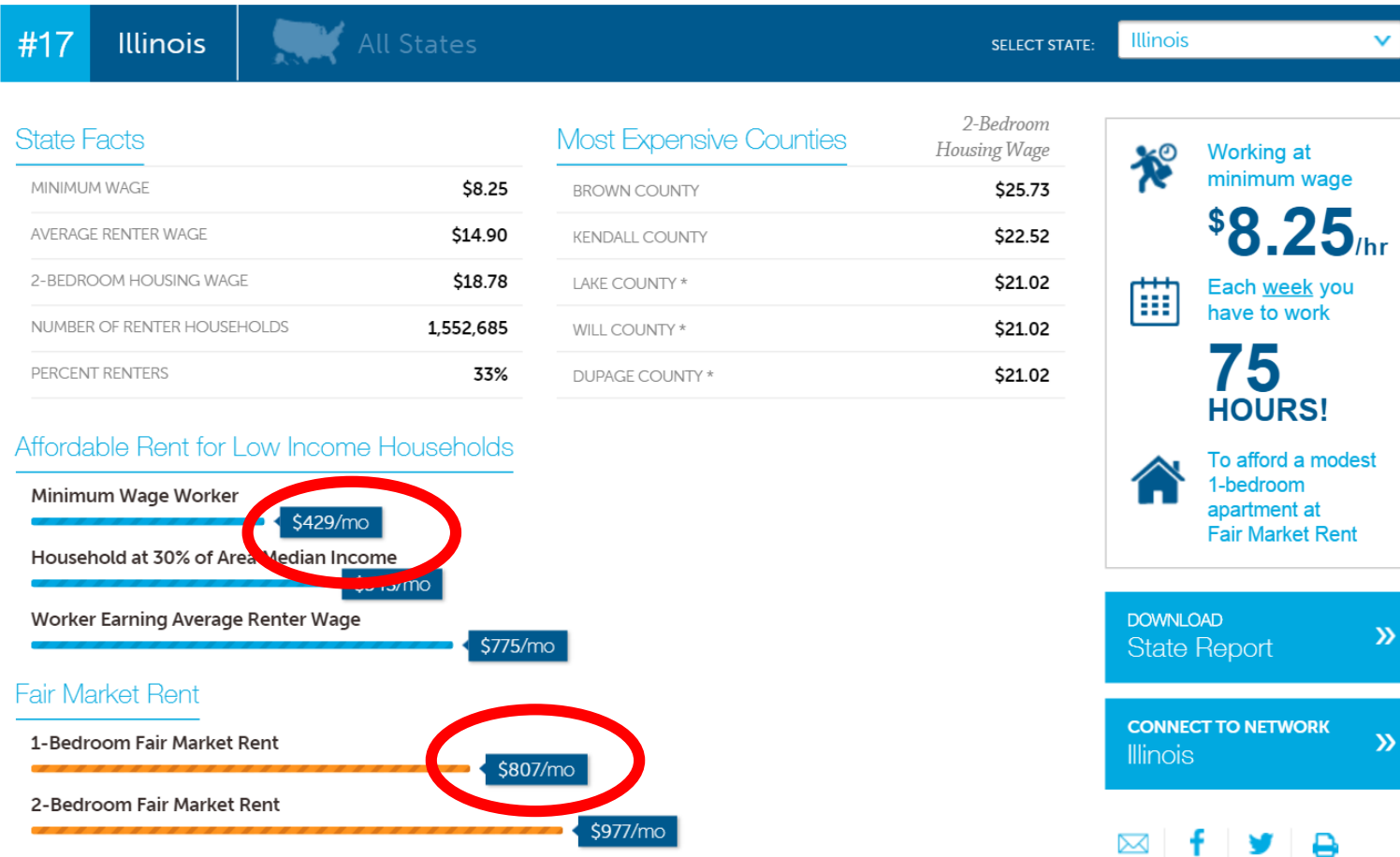
[National Low Income Housing Coalition](#) is NOT
disability-specific, but shows the necessary
income to afford housing across the country.

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

	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

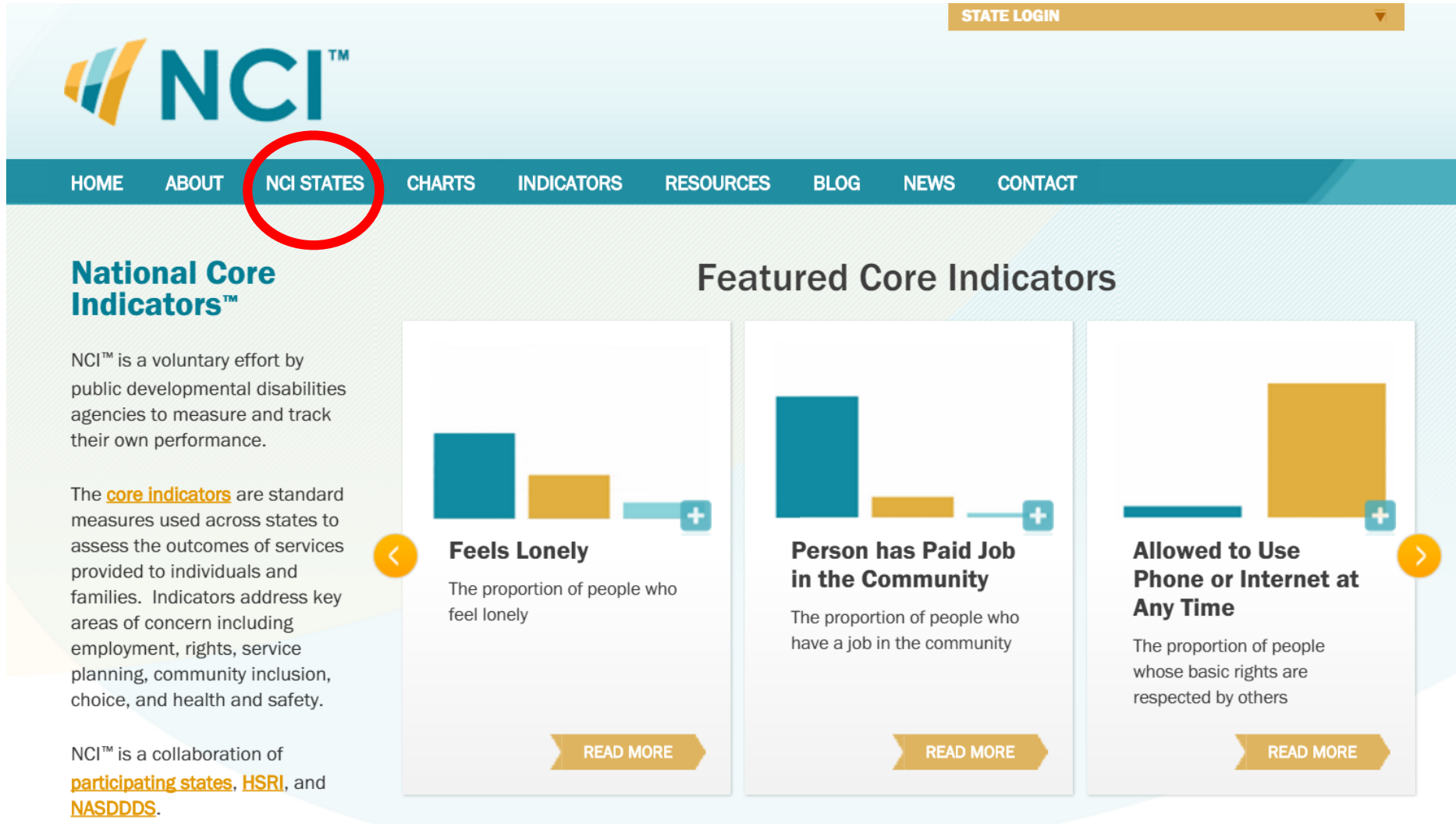
	Illinois	Chicago-Naperville-Joliet HMFA *
ZERO-BEDROOM	\$703	\$812
ONE-BEDROOM	\$807	\$922
TWO-BEDROOM	\$977	\$1,093
THREE-BEDROOM	\$1,260	\$1,393
FOUR-BEDROOM	\$1,465	\$1,624

Annual Income Needed to Afford

	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*



NCI™

STATE LOGIN

HOME ABOUT **NCI STATES** CHARTS INDICATORS RESOURCES BLOG NEWS CONTACT


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



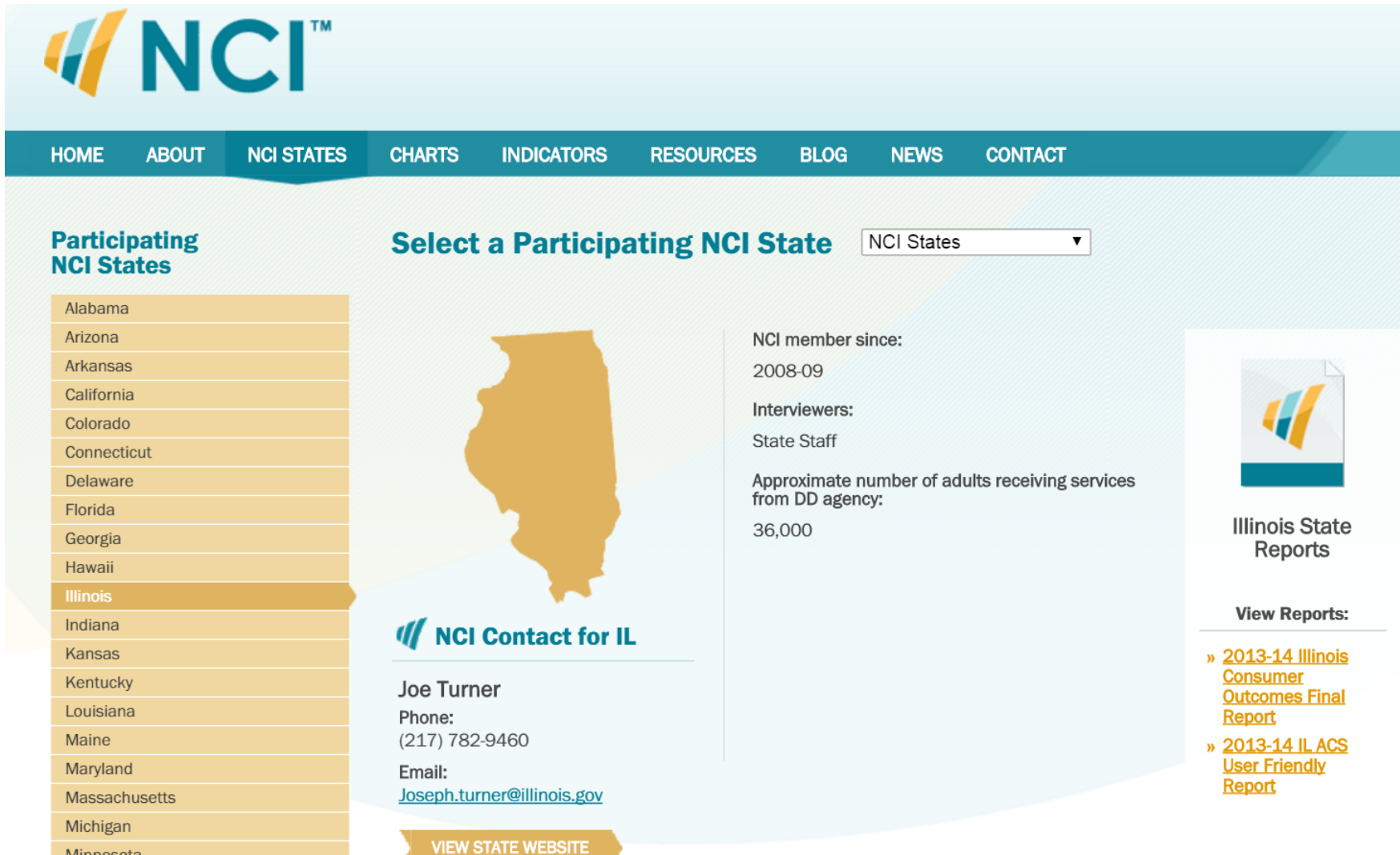
Allowed to Use Phone or Internet at Any Time

The proportion of people whose basic rights are respected by others

READ MORE

[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 interface. At the top is the NCI logo and a navigation bar with links: HOME, ABOUT, NCI STATES, CHARTS, INDICATORS, RESOURCES, BLOG, NEWS, and CONTACT. The 'NCI STATES' section is active, displaying a list of participating states on the left. Illinois is highlighted in the list and on a map. To the right of the map, details for Illinois are provided: NCI member since 2008-09, interviewers as State Staff, and approximately 36,000 adults receiving services from the DD agency. Contact information for Joe Turner is listed, including phone and email. A 'VIEW STATE WEBSITE' button is at the bottom. On the right, a section for 'Illinois State Reports' lists two reports: '2013-14 Illinois Consumer Outcomes Final Report' and '2013-14 IL ACS User Friendly Report'.

NCI™

HOME ABOUT **NCI STATES** CHARTS INDICATORS RESOURCES BLOG NEWS CONTACT

Participating NCI States

- Alabama
- Arizona
- Arkansas
- California
- Colorado
- Connecticut
- Delaware
- Florida
- Georgia
- Hawaii
- Illinois**
- Indiana
- Kansas
- Kentucky
- Louisiana
- Maine
- Maryland
- Massachusetts
- Michigan
- Minnesota

Select a Participating NCI State NCI States ▼

NCI Contact for IL

Joe Turner
Phone: (217) 782-9460
Email: Joseph.turner@illinois.gov

VIEW STATE WEBSITE

NCI member since:
2008-09

Interviewers:
State Staff

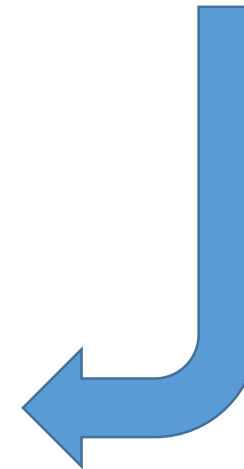
Approximate number of adults receiving services from DD agency:
36,000

Illinois State Reports

View Reports:

- » [2013-14 Illinois Consumer Outcomes Final Report](#)
- » [2013-14 IL ACS User Friendly Report](#)

[National Core Indicators](#) data for most states can be downloaded as a PDF.



Quality of Life: *National Core Indicators*

The screenshot shows the National Core Indicators website. At the top right is a 'STATE LOGIN' button. The navigation bar includes links for HOME, ABOUT, NCI STATES, CHARTS, INDICATORS, RESOURCES, BLOG, NEWS, and CONTACT. On the left, the 'National Core Indicators™' logo is displayed above a paragraph explaining the organization's mission. Below this, a paragraph describes the 'core indicators' as standard measures used across states. At the bottom left, it mentions the collaboration with participating states, HSRI, and NASDDDS. In the center, a 'CHART GENERATOR' button is highlighted with a red circle, with an 'INDICATOR INDEX' link below it. To the right, the 'Featured Core Indicators' section displays three cards, each with a bar chart and a description. The first card, 'Feels Lonely', shows a bar chart with a blue bar and a yellow bar, and a description: 'The proportion of people who feel lonely'. The second card, 'Person has Paid Job in the Community', shows a bar chart with a blue bar and a yellow bar, and a description: 'The proportion of people who have a job in the community'. The third card, 'Allowed to Use Phone or Internet at Any Time', shows a bar chart with a blue bar and a yellow bar, and a description: 'The proportion of people whose basic rights are respected by others'. Each card has a 'READ MORE' button at the bottom.

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](#).

CHART GENERATOR
INDICATOR INDEX

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

[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](#)



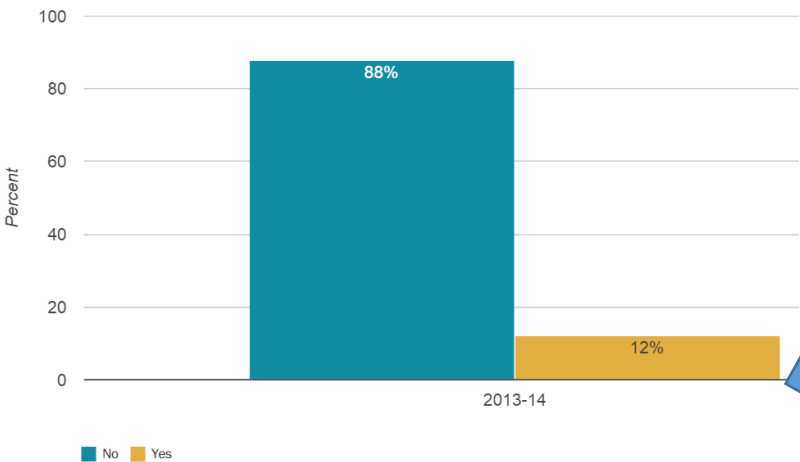
State(s): N/A

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

Quality of Life: *National Core Indicators*

Person in Community Paid Job

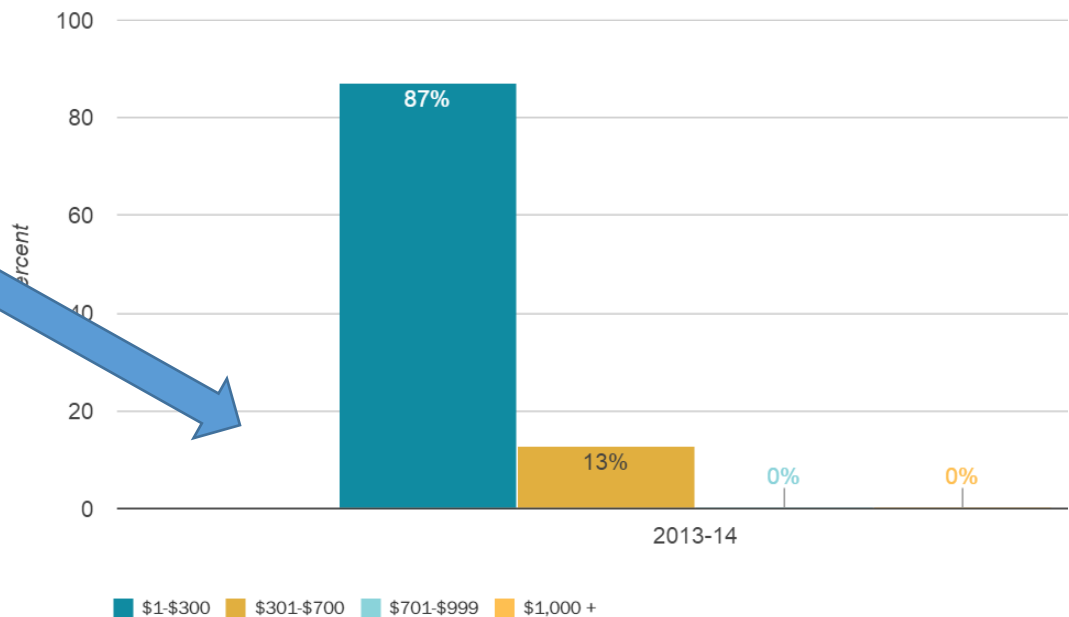
The proportion of people who have a job in the community.



Total Respondents: 336

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!

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

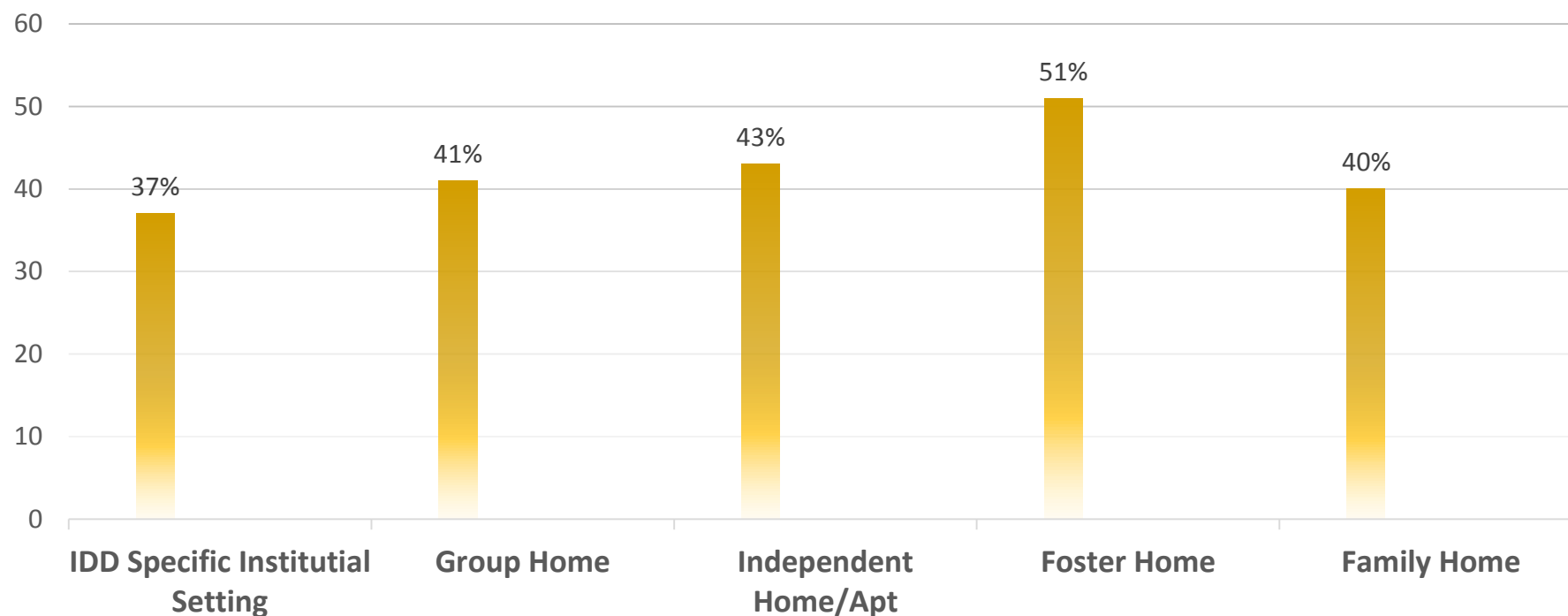
Quality of Life: *National Core Indicators*

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



When disability and abuse intersect, we take action.

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 seek justice for perpetrators

Action Areas

Public awareness, education, law enforcement, and professional development

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.

Project Director

disability and abuse. [\(more\)](#)

[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](#))

[Other Guidebooks](#)

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

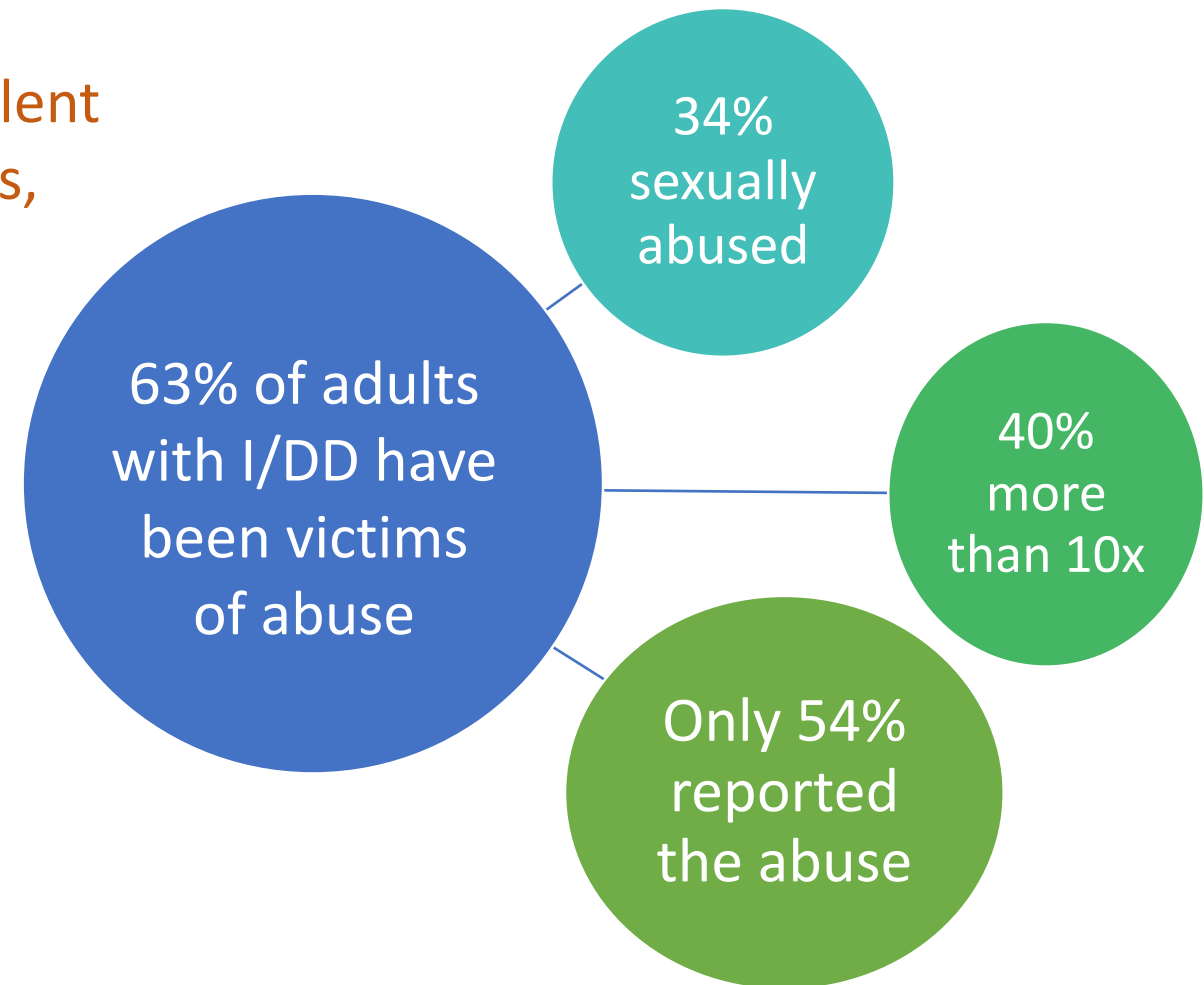
“The bottom line is that abuse is prevalent and pervasive, it happens in many ways, and it happens repeatedly to victims with all types of disabilities.”

Reasons for not reporting:

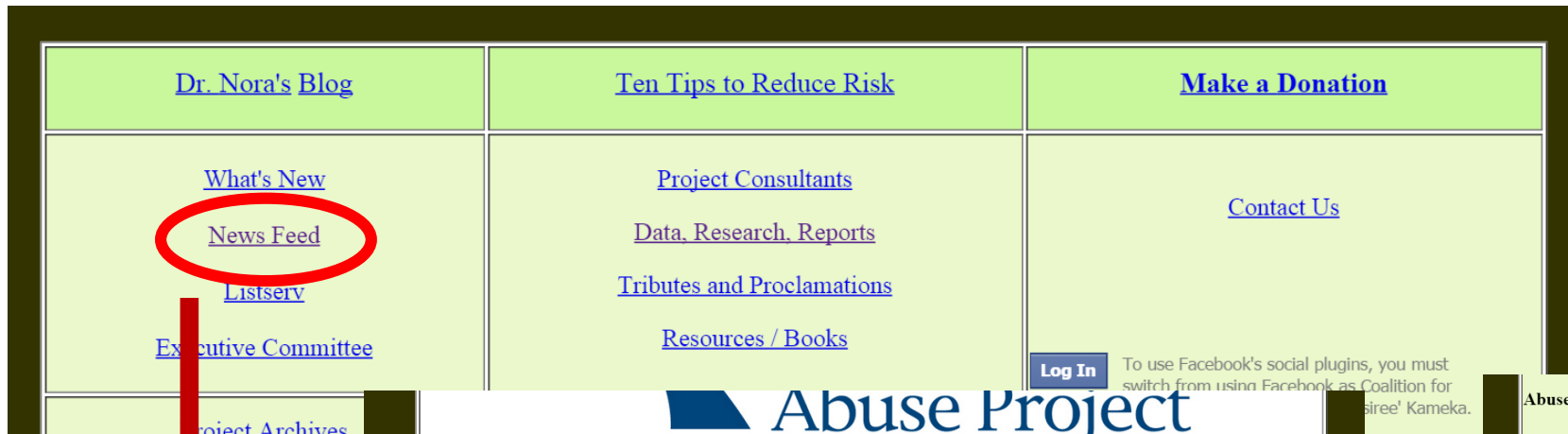
58%
believed
nothing
would
happen

38% had
been
threatened
or were
afraid


33% did
not know
how or
where to
report



Abuse: Disability Abuse Project, 2012 National Survey



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



Abuse Project

When disability and abuse intersect, we take action.

Newsfeed on Disability and Abuse

Prepared by Anne M. Kincaid

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.

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.

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.

Current News

[September 14, 2015](#)

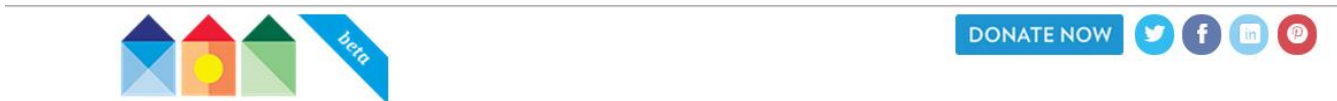
Archives

[September 7, 2015](#)

Abuse/Crime-related

1. "Family Seeking Answers on Autistic Son's Head Injury" --- A Tuscumbia 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](http://www.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!



AUTISM HOUSING NETWORK

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HOUSING

- LIFESTYLE
 - REGION
 - PRIMARY RESIDENTS
 - LEVEL OF SUPPORT
 - SUBMIT A LISTING
- AGRICULTURAL
- URBAN/TRANSIT-ORIENTED
- LIVE-WORK-PLAY
- TRANSITIONAL / COLLEGIATE
- 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](#)



tyl/transitioncollegiate/



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
www.CoalitionForCommunityChoice.org
www.AutismHousingNetwork.org

Desiree Kameka
dkameka@madisonhouseautism.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 Commu

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

