

# HCBS Final Settings Rule & Illinois Statewide Transition Plan

## ICDD PUBLIC COMMENT BUILDER

### Overview

The Home and Community Based Settings (HCBS) Final Rule is a federal policy change announced by the Centers for Medicare and Medicaid Services (CMS) to make sure that people with disabilities have the kinds of services they need in their communities. The Rule requires that the places where people receive HCBS waiver services offer full access to the benefits of community life.



**RIGHT NOW** is your opportunity to provide input on the Statewide Transition Plan (STP) Illinois has developed to come into compliance with the HCBS Settings Final Rule. The State is required to ask for public comments when they make changes to their STP. You can help ensure that the settings rule is implemented fully, so the State provides funding to support transition of HCBS services to meet the settings rules.

**Visit:** <https://www.illinois.gov/hfs/SiteCollectionDocuments/PNforTransitionPlan2020FINAL.pdf>

The revised Statewide Transition Plan is accessible through the HFS website.

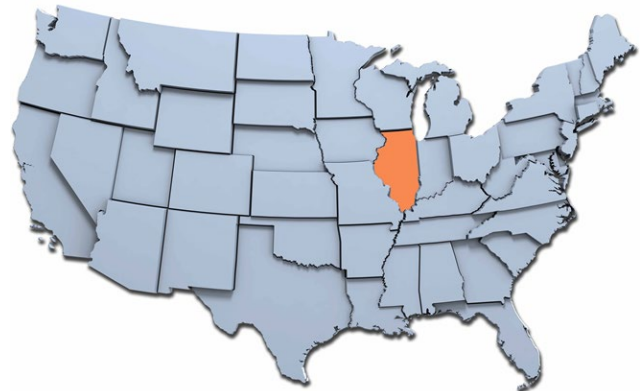
**Visit:** <https://www.illinois.gov/hfs/MedicalClients/HCBS/Transition/Pages/TransitionPlan.aspx#Subhead6>

### Comment Builder Overview

Starting on pg. 5, you are provided a template that will assist you with formulating your public comment so that you can speak up and speak out to the State of Illinois. After learning about the topic, you can now begin building your public comment.

### Hot Points for Advocacy (*Ideas*)

- Assessing settings
- Addressing community capacity
- Stakeholder engagement
- Education & outreach
- Funding for community services
- Person-centered planning
- Capitalize on the opportunity for policy change



## ACTIVITY:

### Think About Your Life and Your Services



The Rule is designed to make sure that the services you receive provide the opportunity for integration and access to the community, choice, individual rights, and independence. You will find a description and examples of these important concepts below. Use the questions included to help you think about whether the services you receive have these qualities and if you need to advocate for changes. You may want to ask your family, friends, or others that know you well to help you answer these questions and record your responses.

**Choice** means that you can select the services and supports that you need, as well as who provides them and where you receive them. You should have options to live and receive services in places that are for people with and without disabilities.

**Integration** and access to the community means that you have the same chances to be an active and included member of your neighborhood and community as someone without disabilities. You should have opportunities to:

- ✓ find competitive employment working alongside people without disabilities
- ✓ participate in local activities
- ✓ access services in the community just like people without disabilities

**Individual rights** include privacy, dignity and respect, and freedom from coercion and restraint. Some of the individual rights you should have are:

- ✓ being able to lock your doors
- ✓ using the phone when you want
- ✓ coming and going as you please
- ✓ having time alone when you want





**Independence** means that you are in charge of making decisions about your life and what you want to do. These decisions include your daily activities, your surroundings, and the people you interact with. Some examples of independence are:

- ✓ setting your own schedule
- ✓ choosing where you want to go
- ✓ controlling your own budget







## QUESTIONNAIRE

Think about your life or the life of your loved one....

CHOICE		
Please add a check mark under the green smiley face if the answer is <b>YES.</b> 😊 Please add a check mark under the red sad face if the answer is <b>NO.</b> 😞		
1. Did you choose where your services are provided? (for example: group home, own home, day program)		
2. Did you choose the services you receive?		
3. Did you choose who provides your services?		
4. Did you choose where you live?		
5. Did you choose who you live with?		
A. If you answered "no," what changes would you make to your services or living arrangement?		
INTEGRATION		
Please add a check mark under the green smiley face if the answer is <b>YES.</b> 😊 Please add a check mark under the red sad face if the answer is <b>NO.</b> 😞		
1. Do you spend time in places where other people living in your community go? (For example: stores, restaurants, bank, house of worship)		
2. Do your service providers support you to do what you want in your community? (For example: go to a gym, visit the library, visit your boyfriend/girlfriend, take a class)		
3. Do you receive services in the same places as people without disabilities?		
4. Do you get to do as much as you want in your community?		
B. If you answered "no," what changes would you make to your services or living arrangement?		

QUESTIONNAIRE CONTINUED...

INDIVIDUAL RIGHTS		
Please add a check mark under the green smiley face if the answer is <b>YES.</b> 😊 Please add a check mark under the red sad face if the answer is <b>NO.</b> 😞		
1. Are you able to have personal space and time alone when receiving services?		
2. Are you able to come and go as you please?		
3. Are you able to have visitors where you live and where you receive services?		
4. Do people listen when you speak up for yourself?		
C. If you answered "no," what changes would you make to your services or living arrangement?		
INDEPENDENCE		
Please add a check mark under the green smiley face if the answer is <b>YES.</b> 😊 Please add a check mark under the red sad face if the answer is <b>NO.</b> 😞		
1. Are you able to choose your own schedule?		
2. Do you choose what you do for fun?		
3. Do you choose how to spend money?		
4. Do you have a chance to make decisions about your life and what you want to do?		
D. If you answered "no," what changes would you make to your services or living arrangement?		

## ICDD Public Comment Builder

### Use the “Hook, Line and Sinker” Approach:

- **Hook:** Details about you or your family (including your disability, where you live, etc.)
- **Line:** Your main concern (and a specific story or fact that shows the problem)
- **Sinker:** What you want changed and how you want it changed

<b>SAMPLE PUBLIC COMMENTS</b>	
<b>Sample “Hot Points” for Advocacy</b>	<b>Sample Comment</b>
<b>Access to more housing options (with full control) in the community</b>	<p><b>Hook:</b> My name is Susie Towns and I am a self-advocate from Chicago Illinois.  <b>Line:</b> I think the plan for Illinois needs to have more information about how people with DD will have more access to community-based housing and supportive housing. When it came time for me to move from my parents’ home, I had no choices but an ICFDD or an Institution. How can we make sure people have access to community housing choices so people who don’t want to live in an ICFDD or an Institution don’t have to? <b>Sinker:</b> I think the plan needs to be clearer about how IL plans to make more housing options available for community services.</p>
<b>Stakeholder Input</b>	<p><b>Hook:</b> I am a self-advocate from Springfield IL. I receive HCBS waiver services through Star Inc. <i>(If comfortable, feel free to mention if you like OR dislike your services, if they do or don’t do a good job, if you do or don’t feel supported)</i>. I am a member of the Illinois Self Advocacy Alliance board. <b>Line:</b> I work really hard to represent self-advocates across the State of IL. One thing that that is important to all of us is having access to information and being in charge of our lives. In regard to the IL STP, I only see one place where HFS/DHS plans to proactively engage one self-advocate in the process going forward. <b>Sinker:</b> People with disabilities should be more involved. First, there should be a plan for how stakeholders will be informed as to the changes they should be expecting. There should also be a plan for how this changes person centered planning, especially if someone is going to have a rights restriction. It has to be documented in the person-centered plan. I think there should be more detail in the plan as to how self-advocates and other stakeholders outside of State government are involved in this entire process. This part of the plan should be better.</p>
<b>Funding Community Services</b>	<p><b>Hook:</b> My name is Sara Jones and I am a senior caregiver in Centralia Illinois.  <b>Line:</b> For many decades, the State of Illinois has been operating dual services for people with DD. The dual services are community and institutional living. Nationally, we are also rated 44th to 51st in providing community services to persons with I/DD in Illinois. There are at least 7,000 people getting no services in Illinois and their caregivers are often 60 years old or more and will at some point not be able to care for their adult child with significant disabilities. <b>Sinker:</b> The STP should include some concrete steps toward increasing the capacity of community services. This likely will require incentivizing providers to develop increased living and day/employment options.</p>



## Sharing Your Story Effectively for Change

Your stories and experiences are among the most powerful tools for change. Sharing them effectively with professionals, legislators and other advocates can make a big impact. Use the space below to fill in your own information to this approach. Go back to boxes A, B, C and D in the activity section for ideas on topics you would like to comment on.

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### What Will You Say? Build Your Comment...

#### Hook:

My name is \_\_\_\_\_ **(PROMPT: Add a little about yourself)** I live in a \_\_\_\_\_  
**(home/CILA/apartment)** in \_\_\_\_\_ **(town)**. **(PROMPT: What is especially important for your services?)** I need support to \_\_\_\_\_ **(get around, communicate, read and understand, take my medications, with meals, getting dressed, etc.)**

#### Line:

**(PROMPT: Issue you think is important and needs to be in Illinois's plan for community-based services)** I am a person who finds \_\_\_\_\_ very important in my life. This is why it is so important to me that I have this right/ am able to do these things in the community \_\_\_\_\_.

#### Sinker:

**(PROMPT: What exactly you want to see in Illinois' community-based service plan).** Illinois's HCBS plan should state how the service system will be able to \_\_\_\_\_ **(fill the need or gap you talked about)**. I feel \_\_\_\_\_ **(the type of service, how a rule should change, etc.)** ought to be written into the plan. Thank you for the chance to share my personal story and what I feel is important for the plan.

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### Submit Your Comment:

The deadline to submit a public comment is March 5, 2020. Comments may be submitted online [HFS.SWTransitionPlan@illinois.gov](mailto:HFS.SWTransitionPlan@illinois.gov) or written comments may be mailed to:



The Illinois Department of Healthcare and Family Services, Attn: Waiver Management  
201 South Grand Ave East, FL 2  
Springfield, IL 62763

Persons who are unable to access the Internet may request a hard copy of the revised draft plan by calling HFS at (217) 524-4148. The State **NEEDS** to hear your voice!

**PLEASE ALSO SHARE YOUR COMMENT WITH THE ILLINOIS COUNCIL ON DEVELOPMENTAL DISABILITIES BY EMAILING [ICDDINFO@Illinois.gov](mailto:ICDDINFO@Illinois.gov).**