

# Research

Stakeholders' Knowledge of the Home and  
Community Based Services (HCBS) Settings Rule



**Stakeholders' Home and Community Based  
Services (HCBS) Settings Rule Knowledge**

*Research and Practice for Persons with Severe Disabilities*

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Citation:  
Friedman, C. (2018). Stakeholders' Home and Community Based Services Settings Rule Knowledge. *Research and Practice for Persons with Severe Disabilities*, 43(1), 54-61.  
<https://doi.org/10.1177/1540796917743210>

*Acknowledgments:*

Research reported in this publication was supported by a grant from the Illinois Council on Developmental Disabilities. This research was also sponsored in part by the United States Department of Health and Human Services, Administration for Community Living (ACL), National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) Grant # 90AR5023. The content is solely the responsibility of the author and does not necessarily represent the official views of either funder and endorsement should not be assumed.

### Abstract

Medicaid Home and Community Based Settings (HCBS) waivers provide the majority of long-term services and supports for people with intellectual and developmental disabilities (IDD). The relatively new HCBS settings rule (CMS 2249-F/2296-F) requires *meaningful* community integration of people with disabilities who receive HCBS services. States are required to develop and submit compliance transition plans, which document these complex new programs. Public comment periods provide advocates the opportunity to impact states' rules by ensuring plans are truly community based. Yet, the lengthy and technical rule can be inaccessible for people with disabilities and their allies. Because knowledge of the HCBS settings rule can be crucial for people with IDD to access their rights, the aim of this study was to explore HCBS settings rule knowledge of people with IDD and key stakeholders. Our findings confirmed there is a need to make the HCBS settings rule more accessible to those most affected by the changes – people with IDD and family members of people with IDD. Doing so is a necessary first step to promote advocacy regarding its implementation.

*Keywords:* Medicaid; Home and Community Based Services; HCBS final settings rule; people with disabilities; public policy; community living

### **Stakeholders' Home and Community Based Services (HCBS) Settings Rule Knowledge**

The majority of federal funding for people with intellectual and developmental disabilities (IDD) in the United States is from Medicaid (Braddock et al., 2015). Medicaid Home and Community Based Services (HCBS) 1915(c) waivers, in particular, provide approximately two-thirds of Medicaid funding for people with IDD (Braddock et al., 2015). Medicaid HCBS 1915(c) waivers were developed in 1981 as an alternative to institutional placements; they allow states to ‘waive’ the three main provisions of the Social Security Act (i.e., state-wideness, comparability, and income and resource rules) in order to create customized programs tailored to particular underserved populations with complex needs, such as people with IDD, that would otherwise require institutionalized care (U.S. Department of Health and Human Services, 2000). States have the flexibility to determine waivers’ target groups, services, participant direction, provider qualifications, health and welfare strategies, and cost-effective delivery systems (Disabled and Elderly Health Programs Group et al., 2015).

HCBS waiver funding has far surpassed institutional funding to become the largest provider of long-term services and supports (LTSS) for people with IDD because of the cost effectiveness, the benefits of community living, and the preferences of people with IDD (Braddock et al., 2015; Rizzolo, Friedman, Lulinski-Norris, & Braddock, 2013). Despite the advantages of HCBS waivers, people with IDD still face large disparities when it comes to community integration. For this reason, the Department of Health and Human Services’ Community Living initiative introduced a new HCBS regulation in 2009. The HCBS final settings rule (CMS 2249-F/2296-F) aims to “develop and implement innovative strategies to increase opportunities for Americans with disabilities and older adults to enjoy meaningful

community living” (Medicaid Program, 2014, n.p.). As such, the rule shifts “away from defining home and community-based settings by ‘what they are not,’ and toward defining them by the nature and quality of participants’ experiences” (Centers for Medicare and Medicaid, 2014, p. 2). The rule, which was implemented in 2014, “establish[ed] 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” (Centers for Medicare and Medicaid, 2014, p. 2).

The HCBS settings rule involves regulatory changes that states must implement before 2022 if they are to continue to receive Medicaid funding (Medicaid Program, 2014; Neale, 2017). The rule requires community integration and has strict regulations enforcing what is and what is not a community-based setting. Moreover, States are required to provide community opportunities that are *meaningful* (Medicaid Program, 2014). Under these regulations settings must allow people with disabilities to interact with nondisabled people other than paid staff (Medicaid Program, 2014). The rule also mandates that people with disabilities have the same access to community as nondisabled people, which means that they must be able to choose where and with whom they live (State of Tennessee, n.d.). People with disabilities are also entitled to keys to their homes and their own money. They must also have choice about factors such as how they decorate their rooms, where they work, when they have visitors, what services they receive, and so forth. For these reasons, the rule is centered on person centered planning (Medicaid Program, 2014).

Although the settings rule’s regulations may appear straightforward, ensuring that people with disabilities have *meaningful* community inclusion and integration requires a complex overhaul of a system where currently “people with IDD have merely become physically relocated into the community and not meaningfully integrated in and engaged with the

community” (Friedman & Spassiani, 2017). For this reason, the Centers for Medicare and Medicaid (CMS) requires states to develop and submit compliance transition plans, which document these complex new programs. As of the June 2017, only the state of Tennessee had received approval from CMS; the remaining states have either had their transition plans rejected for not complying with the regulations or have not yet submitted plans to CMS (Centers for Medicare and Medicaid Services, n.d.).

When developing transition plans, states are required to open the plans up for public comment every time CMS asks for adjustments. States must then address the comments accordingly before submitting the plan to CMS. Public comment periods provide advocates and other stakeholders with the opportunity to impact states’ rules and regulations regarding community integration. As such, advocates and stakeholders also have the opportunity hold states accountable to ensure LTSS is meaningful and truly community based. Yet, as the rule is lengthy and technical, it is very inaccessible for people with complex support needs and their allies. Because knowledge of the HCBS settings rule can be crucial for people with IDD to access their rights, the aim of this study was to explore rule knowledge of people with IDD and key stakeholders and the factors that facilitate or inhibit ones’ knowledge of the HCBS settings rule. Doing so is a necessary first step in order to reduce knowledge disparities about this critical regulation and to promote advocacy regarding its implementation.

## **Methods**

### **Recruitment**

People with intellectual and developmental disabilities (IDD), family members of people with IDD, and professionals working with people with IDD (e.g., direct support professionals, individual service coordinators, case managers) were recruited through Independent Service

Coordination (ISC) centers charged with ensuring “services and supports are responsive to the unique needs and desires of each individual and to effectively promote independence, community inclusion, and self-determination” (Champaign County Regional Planning Commission, 2009, p. 2). Participants were recruited through flyers and word of mouth that advertised an information session about the HCBS settings rule held throughout the state of Illinois.

Of the 86 session attendees, seventy people participated in the survey (Table 1). The majority of participants were white ( $n = 67$ ; 95.7%), and women ( $n = 51$ ; 72.9%). Most participants were family members of someone with a disability ( $n = 40$ ; 47.1%), while the number of participants with disabilities and professionals was evenly split ( $n = 15$  each; 21.4% each).

### **Data Collection Methods**

Data were collected via a 15-question survey developed by the researchers, approved by the IRB (Appendix A). Questions were designed to collect information about knowledge of the features of the HCBS settings rule as well as their demographic information. Demographic information included home setting; number of housemates; involvement in disability advocacy (yes; no); and, self-reported knowledge of the settings rule (never heard of it; heard of it but do not know much; know a little; know a lot).

These surveys were examined in advanced for accessibility and readability by: (a) a person with IDD who is a world renowned self-advocacy specialist, (b) a member of the Illinois Developmental Disabilities Council, and (c) four researchers who have extensive experience working with people with IDD. They were adjusted based on reviewer feedback accordingly

Before the information session began, a script was read that described the purpose of the study and ensured attendees that participation was on a voluntary basis with no penalty for not participating. Paper surveys were then distributed to all interested attendees. After participating in the survey the subjects were thanked for their participation and the separate information session (not lead by the research team) began.

### **Analysis**

Participants' answers to the knowledge questions were 'dummy' coded for correct and incorrect and then summed to comprise participants' total knowledge score. Descriptive statistics were then run. Crosstab analyses were used to examine HCBS settings rule knowledge by participant group.

### **Results and Discussion**

The aim of our study was to determine what factors facilitate or hinder key stakeholders' knowledge of the HCBS settings rule so that future training and advocacy programs could focus on reducing these knowledge disparities.

Approximately three-quarters of participants were from a big town or city (larger than 2,500 residents). Most participants with disabilities lived in group homes ( $n = 7$ ; 46.7%), and their own homes ( $n = 5$ ; 33.3%), with fewer living in family homes ( $n = 3$ ; 20.0%). Slightly more than half of participants were involved in disability advocacy ( $n = 36$ ). According to participants' self-reported knowledge, most people had never heard of the HCBS settings rule ( $n = 28$ ; 40.0%), or had heard of it, but did not know much about it ( $n = 20$ ; 28.6%); fewer knew a little ( $n = 14$ ; 20.0%) or a lot ( $n = 8$ ; 11.4%) about the rule.

There were wide knowledge differences across the three stakeholder groups of participants: professionals working in a disability industry ( $m = 12.48$  out of 15,  $sd = 2.76$ );

people with disabilities ( $m = 5.64$  out of 15,  $sd = 4.67$ ); and families members of people with disabilities ( $m = 6.24$  out of 15,  $sd = 5.24$ ). As would be expected, professionals, those with more education, and those involved in advocacy work were significantly more likely to know about the rule than those most affected by the changes – people with IDD, and family members of people with IDD (Table 2). In fact, people with disabilities not only scored the lowest on the questionnaire on average, it was also rare for the participants with disabilities to have any self-reported familiarity with the rules.

Our findings also revealed the people with disabilities who lived in group homes – the participant group most likely impacted by the HCBS settings rule – also had the least knowledge about the rules, with an average of 32.4% correct (Table 2). Many provider organizations are still grappling with how to implement these changes, especially within already restrictive funding structures; as indicated by the knowledge gaps revealed in our findings, it appears providers have yet to present the people with serve with information about the rights they are entitled to according to the rules. Regardless, these disparities must be accounted for by 2022, the deadline for settings rule implementation.

When interpreting our findings a number of limitations should be noted, particularly related to our sample. First, our sample participated on a volunteer basis and already had an interest in the rules; there is a chance of self-selection bias as a result. Moreover, our sample was also not representative of the disability community or United States at large. The overwhelming majority of our participants were family members, and white women. Future studies should strive for a more representative sample to determine if there are differences in terms HCBS settings knowledge. This may especially pertinent as research has indicated that women view people with disabilities more favorably, and women siblings report a closer relationship with

their sibling with a disability (Hodapp, Urbano, & Burke, 2010; Hirschberger, Florian, & Mikulincer, 2005). Another limitation was that none of the participants resided in an institutional setting. As these settings, such as Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICFs/IID), are not community based and do not fall under HCBS, it is likely people with disabilities in these settings would know less about the HCBS settings rule. Our participants were recruited on a volunteer basis so this was a limitation; future research should seek out these participants in particular. It may be especially pertinent to explore the settings rule knowledge of family members of people with disabilities who live in institutional settings to determine if there is a significant relationship between institutional/community placement, and knowledge of the ideals the HCBS settings rule puts forth.

The aim of this study was to explore knowledge of the HCBS settings rule among those who if affected – key stakeholders. However, future research would benefit by also adding a comparison group of the general public to determine if and how those connected to the disability community understand the HCBS settings rule differently than nondisabled people not connected to the disability community.

Our finding that there is a significant relationship between self-reported knowledge and actual knowledge of the HCBS settings rule may suggest that one of the largest gaps is familiarity, that is actually hearing about the rule, not necessarily its complexity. Those who believed they knew about the rule actually did (Table 2), suggesting when broken down the general requirements of the rule are not so complex that people are not able to comprehend it. Although it may appear obvious, we are optimistic about this finding as we believe it suggests that training and advocacy programs about the rule, especially those which pay attention to the

factors unearthed in our findings, can successfully expand knowledge about the HCBS settings rule (Friedman, in press).

In order to expand the knowledge of people with disabilities, family members, and providers, we suggest states offer training programs about the rights granted to people with disabilities under the HCBS settings rules, such as Friedman (in press). Although any program would be better than none, based on our findings for the most efficiency we believe each of these programs should be designed and targeted to individual populations, such as people with IDD who live in group homes. However, we recognize that in this limited fiscal landscape, these types of information sessions may not be high on the priority list for states. Therefore, we would encourage self-advocacy organizations to take up the charge, perhaps utilizing a train-the-trainer model (e.g., Frawley & Bigby, 2014; Marks, Sisirak, & Chang, 2013; Magaña, Lopez, & Machalicek, 2013; Magaña, Lopez, de Sayu, & Miranda, 2014; etc.) where experienced self-advocates train younger self-advocates to help spread the word in their communities. A wide number of accessible resources are available about the rules for these programs; for example, see HCBS Advocacy (n.d.) or The Council on Quality and Leadership (2017).

States and/or CMS also need to provide more clarity about what constitutes ‘meaningful’ community participation in the rules. Not only do many people with IDD struggle to be meaningfully included in the community (Friedman & Spassiani, 2017), without state guidance many service organizations are unsure of the best way to implement the rules. Moreover, service organizations are left wondering where they will get the money to implement the changes, many of which could require significant shifts in the physical and operational infrastructures of their agencies. Outreach about the HCBS settings rule is necessary both to ensure agencies are

following the guidelines set forth, and to actively engage people with disabilities in advocating for their rights.

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Table 1  
*Demographics and Descriptive Statistics (n = 70)*

	%	n	M	SD
Gender				
Man	25.7	18		
Woman	72.9	51		
Race				
White	95.7	67		
Black	1.4	1		
American Indian and/or Alaska Native	1.4	1		
Some other race	1.4	1		
Age			52.0	14.7
Participant group				
Family member of someone with a disability	57.1	40		
Person with disability	21.4	15		
Professional	21.4	15		
Education				
High school education	27.1	19		
College education or trade/vocational school	40.0	28		
Graduate education	31.4	22		
Hometown				
Big town or city (larger than 2,500)	74.3	52		
Very small town or in the country (less than 2,500 people)	25.7	18		
Number of housemates			2.0	1.9
Involved in disability advocacy	51.4	36		
Self-reported knowledge				
Never heard of it	40.0	28		
Heard of it but do not know much	28.6	20		
Know a little	20.0	14		
Know a lot	11.4	8		

Table 2

*Percent of HCBS Settings Rule Knowledge Questions Correct By Group*

Factor	All	Professionals	People with disabilities	Family members
<b>Education</b>				
High school education	31.9%	53.3%	32.2%	23.3%
College education or trade/vocational school	69.1%	86.7%	70.0%	51.1%
Graduate education	60.6%	91.1%	--	47.1%
<b>Hometown</b>				
Big town or city (constant)	53.7%	84.4%	38.3%	41.8%
Very small town or in the country	62.2%	82.0%	33.3%	42.9%
<b>Home setting (people with disabilities only)</b>				
Own home or apartment	--	--	45.3%	--
Family home	--	--	36.7%	--
Group home	--	--	32.4%	--
<b>Involved in disability advocacy</b>				
Not involved	39.1%	86.7%	27.5%	28.6%
Involved	71.1%	82.1%	51.1%	59.6%
<b>Self-reported knowledge</b>				
Never heard of it	32.3%	33.3%	36.3%	33.0%
Not much	56.9%	96.7%	40.0%	49.0%
A little	80.5%	84.0%	--	68.9%
A lot	91.7%	91.7%	--	--

## Appendix A

### Questions and Response Types for Survey Administered

**What is your Race/Ethnicity? (check all that apply):** (White, Black or African American, American Indian and/or Alaska Native, Asian, Native Hawaiian & Other Pacific Islander, Hispanic or Latino)

**I am a (check one):** (Woman, Man, Prefer not to say)

**I identify as having a disability (check one):** (Yes, No, Prefer not to say)

**I am a family member of someone with a disability (check one):** (Yes, No, Not sure)

**What best describes your educational level? (Mark one.)** (Some high school, High School Diploma or GED, Trade/Vocational School, Some College, College degree, Some Graduate School, Graduate Degree)

**I live in a (check one):** (Big town or city (larger than 2,500 people), A very small town or in the country (less than 2,500 people))

**I live in (check one):** (My own home or apartment, With my parents or family, In a group home (with less than 8 people), In an ICF/DD (with more than 8 people), Not sure)

**Are you involved in disability advocacy?** (Yes, No, Not sure)

**How familiar are you with the HCBS settings rule?** (Never heard of it, Heard of it, but do not know much, Know a little, Know a lot)

**Does the HCBS settings rule say people with disabilities must have full access to the community?** (Yes, No, Not Sure)

**Does the HCBS settings rule say services must be person-centered (must be what the person with disabilities really wants)?** (Yes, No, Not Sure)

**Does the HCBS settings rule say people with disabilities must be allowed to control their lives?** (Yes, No, Not Sure)

**Does the HCBS settings rule say group homes must serve at least 10 people?** (Yes, No, Not Sure)

**Does the HCBS settings rule say people with disabilities are not allowed to have keys to their homes?** (Yes, No, Not Sure)

**Does the HCBS settings rule say people with disabilities are only allowed to have visitors at certain times?** (Yes, No, Not Sure)

**Does the HCBS settings rule say people with disabilities are not allowed to manage their money?** (Yes, No, Not Sure)

**Are ICF/DDs (Intermediate Care Facilities for Developmental Disabilities) considered community-based settings?** (Yes, No, Not Sure)

**According to the HCBS settings rule, people with disabilities are allowed to**

**Choose where to live** (Yes, No, Not Sure)

**Choose who to live with** (Yes, No, Not Sure)

**Choose what to do during the day and at night** (Yes, No, Not Sure)

**Choose where to work** (Yes, No, Not Sure)

**Make a choice for somebody else** (Yes, No, Not Sure)

**Choose what services they receive** (Yes, No, Not Sure)

**Choose who provides their services** (Yes, No, Not Sure)