



# HOME AND COMMUNITY-BASED SETTINGS RULE

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*Evaluating Utah's Transition Process  
An Opportunity for Inclusion*



205 North 400 West | Salt Lake City, Utah 84103  
800.662.9080 | fax 801.363.1347 | [www.disabilitylawcenter.org](http://www.disabilitylawcenter.org)

## A Call for Action

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As the State's Protection and Advocacy Agency, the Disability Law Center (DLC) advocates for the full inclusion of people with disabilities by promoting comprehensive, quality community-based services as an alternative to institutionalization. People with disabilities must have choices regarding where and who they live with, the ability to make decisions in their daily lives, and the opportunity to be independent and actively participate in their communities. That is why we applaud the Centers for Medicare & Medicaid Services' (CMS) new Home and Community-Based Settings Rule. We believe the rule makes meaningful advances to ensure that individuals with disabilities have real opportunities to live, play, and work in the community.

The following report details the findings from the DLC's year-long assessment of the State's efforts to comply with the new settings rule. The State has until 2019 to comply with the settings regulations, and these efforts are primarily being led by the Division of Medicaid and Health Financing (DMHF).

The results of our survey, coupled with the State's lack of progress over the last year, has led us to make a call for action. Our survey showed that approximately 20% of settings may require heightened scrutiny before they can be considered home and community-based, in addition many more require significant changes to come into compliance. We also identified considerable systemic barriers that the State must address. Given the extensive changes that must take place, we are concerned the State's current level of engagement will not be sufficient to reach compliance within the required timeframes.

We wish to emphasize that at each of the settings we visited, it was clear staff wanted to provide the highest quality services. This was reflected in client interviews that demonstrated a high level of consumer satisfaction with their service provider. However, client interviews also revealed that consumers often desired more opportunities for community integration than afforded by the State's service system.

Despite the best of intentions, as presently constituted, many providers are unable to offer the degree of integration required by the rule. These providers will need assistance from the State to comply with the rule. Unfortunately the State's hands off approach to the transition process leaves open the very real possibility that providers, and the system as a whole, will run out of time. This would impact not only providers, but the thousands of consumers and families that depend on these services.

If immediate and thoughtful action is taken, there is still time within the transition process to ensure compliance with the new settings rule and improve the quality of our home and community-based service system. This will require leadership by DMHF to address difficult issues such as integrated and competitive employment opportunities, attracting and retaining quality staff, lack of funding, and Division of Services for People with Disabilities (DSPD) policies that do not comport with the rule. It is our hope this report will meaningfully advance the transition process and will result in the changes necessary to ensure the vitality of our service system.

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## A Thank You to Providers

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We wish to thank the service providers who participated in our survey. The feedback they provided was invaluable and we appreciated their candor and openness during our conversations. Each service provider we visited with demonstrated a commitment to helping individuals with disabilities and worked to provide the highest caliber services to their clients. We enjoyed meeting the many wonderful staff members who provide services to Utahns with disabilities and we thank them for their time and feedback.

## Overview of the HCBS Settings Rule

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On January 10, 2014, CMS issued a final rule to define and describe the requirements for Home and Community-Based Settings (“HCBS”). The purpose of the rule is to enhance the overall quality of HCBS programs, add protections for individuals receiving services, and to carry out CMS’s intent that individuals receiving HCBS have full access to the benefits of community living and are able to receive services in the most integrated setting.<sup>1</sup>

At the heart of the rule change is a focus on community integration that acknowledges a state’s responsibilities under the Americans with Disabilities Act (“ADA”) and *Olmstead*.<sup>2</sup> In *Olmstead v. L.C.* the Supreme Court affirmed a state’s obligation under Title II of the ADA to serve people with disabilities in the most integrated setting appropriate to their needs.<sup>3</sup> In the preamble to the final rule, CMS recognizes the new settings rule as a tool to assist states in fulfilling their obligation under the ADA, section 504 of the Rehabilitation Act, and *Olmstead* to serve individuals in integrated settings.<sup>4</sup>

Additionally, the rule seeks to ensure that institutional settings are not paid for using HCBS dollars. This is a key distinction because institutional care is part of the State Medicaid plan<sup>5</sup> which means these services must be provided if an individual meets the eligibility criteria. HCBS services are an alternative to institutional care and are provided through waivers. Waivers allow the State to limit the number of HCBS recipients.<sup>6</sup> These limits have resulted in a waiting list for services of approximately 2,000 individuals and an average wait time of 6.25 years.<sup>7</sup> For those individuals wishing to receive services immediately, institutional care is available at any time. But for those individuals wishing to remain at home and in their communities, they must endure long wait times before receiving services. Therefore, it is critical the State ensure that all HCBS settings truly are home and community-based.

To qualify as an HCBS provider under the new rule a setting must be able to demonstrate all of the following qualities:

1. 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.
2. 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.

3. Ensures an individual's rights of privacy, dignity and respect, and freedom from coercion and restraint.
4. 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.
5. Facilitates individual choice regarding services and supports, and who provides them.<sup>8</sup>

The new rule also addresses those settings that may have institutional qualities. Settings that are located in a building that is also a publicly or privately operated facility that provides inpatient treatment, or 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 from the broader community will be presumed to be a setting that has the qualities of an institution.<sup>9</sup> To overcome this presumption the setting must go through a process called heightened scrutiny, in which CMS determines, based on information presented by the State, that the setting does not have the qualities of an institution and does have the qualities of a home and community-based setting.<sup>10</sup>

All HCBS settings must be in compliance with the new rule by 2019. The process of bringing settings into compliance has been termed "transition." The transition process requires all states to write a plan describing what measures the State will take to assess compliance and make those changes necessary to conform to the new rule.<sup>11</sup> The transition plan must be available for public comment for consumers, providers, and other stakeholders to review and submit input.<sup>12</sup>

Importantly, the public comment process gives our State the opportunity to consider how services are currently being delivered and look for meaningful solutions to improve services and ensure individuals are integrated within their communities. We believe this process should not happen in a vacuum, but rather as part of a community conversation with state officials, providers, consumers, and family members. The new settings rule is a rare opportunity to transform the service system and we as a state should capitalize on this moment to make changes that will improve the lives of all HCBS recipients.

## Survey Methodology

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The new settings rule requires states to gather public input throughout the transition process. Specifically, CMS has encouraged states to seek input from a variety of stakeholder groups including protection and advocacy systems. As the Protection and Advocacy Agency for the State of Utah, the DLC is uniquely suited to provide assistance and input into the transition process. Many of the clients we represent receive services in home and community-based settings. As part of this work, our agency has a detailed understanding of the legal and statutory requirements that apply to home and community services.

In order to provide the State with comprehensive feedback, the DLC initiated a survey of service providers in the spring of 2015 to evaluate our State's current level of compliance with the new rule as well as identify barriers to integration within the State's service system. Our survey focused

exclusively on providers and consumers under the Community Supports Waiver. The Community Supports Waiver is the State's largest waiver, and assists approximately 4,800 Utahns with intellectual disabilities and related conditions to remain at home and in community-based settings.<sup>13</sup> Our survey included 11 providers and 13 different settings. Providers were randomly selected from a stratified sample, and included residential and non-residential providers in rural and urban settings. Over the course of our survey we made onsite visits to each setting and interviewed providers and consumers using a survey tool that included exploratory questions from CMS.

## Summary of Findings

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During our survey we identified several reoccurring themes or trends that were common to most service providers. We found that many service providers are lacking information about the new settings rule. While providers were aware of the settings rule generally, a majority felt there was not sufficient information from the State about the specific changes that will be made or how providers will be impacted. Many providers also had questions concerning how programs such as Employment First would interact with the new requirements.

Another common theme that emerged from our conversations was a lack of resources. Of the 13 settings we visited, 11 indicated a lack of funding as a barrier to integration and high quality services. Many providers noted that, while the pay increase for direct care staff was beneficial, the pay rates are still very low. This impacts a provider's ability to attract and retain staff. Providers also consistently commented that travel reimbursement rates are low, which creates barriers to helping individuals access community services and events.

We learned that it is also necessary to speak with consumers to determine a provider's level of compliance. This is consistent with CMS guidance which states that the final rule moves away from defining HCBS settings by what they are not, and toward defining them "by the nature and quality of individuals' experiences."<sup>14</sup> Often consumers were able to validate information given by a provider. But in several instances consumers provided a different view point regarding a provider's level of compliance. A compliance process that does not include a mechanism to independently capture consumer feedback would undermine those provisions of the rule that seek to empower consumers to have more control and choice over the services they receive.

We also found across all providers, that nearly every individual we surveyed was generally happy with their service provider. Although we found consumer satisfaction did not always indicate compliance with the settings rule, it was apparent from our consumer interviews that providers are very caring and truly passionate about helping Utahns with disabilities. We commend the many dedicated staff and service providers who work to improve the lives of individuals with disabilities.

## Measures of Compliance

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At each site we interviewed staff and clients to gauge compliance in the areas of: (1) integration in the community; (2) individual choice; (3) individual rights; (4) autonomy; and (5) choices about services and providers. The indicators of compliance were drawn from guidance from CMS and included:

- **Integration in the community:** Does the setting provide opportunities for activities in integrated community settings? Does the setting afford opportunities for individuals to access information about community activities? Are individuals receiving HCBS in an area of the setting that is fully integrated with individuals not receiving Medicaid HCBS? Does the setting allow and encourage visitors from the greater community to be present? Are individuals allowed to come and go at any time? Are individuals able to shop, attend appointments, attend religious activities, and visit family and friends as they choose?
- **Individual choice:** Does the setting reflect the individual's needs and preferences? Was the individual given a choice of available options regarding where to receive services? Do clients have individualized schedules that reflect their needs and preferences?
- **Individual rights:** Is all information about individuals kept private? For example, there are no posted schedules of individuals for physical therapy, medications, restricted diet, etc., in a general open area. Do staff regularly interact with clients in a respectful and dignified manner? Are clients comfortable discussing concerns with staff?
- **Autonomy:** Are there locked doors or other barriers preventing individuals' entrance to or exit from certain areas of the setting? Does the setting afford opportunities for individuals to choose with whom to do activities? Does the setting allow individuals to have meals/snacks at the time and place of their choosing?
- **Choices about services and providers:** Was the individual given a choice regarding the services, provider and setting? Was the individual given the opportunity to visit multiple settings when selecting a provider?

During our visits we observed that only a very small percentage of providers were able to demonstrate full compliance with the new rule. Generally, residential providers required fewer changes to come into full compliance than non-residential providers. However, in both settings we observed providers that had the effect of isolating individuals from the broader community such that these settings should be subjected to heightened scrutiny.

## Non-Residential Findings

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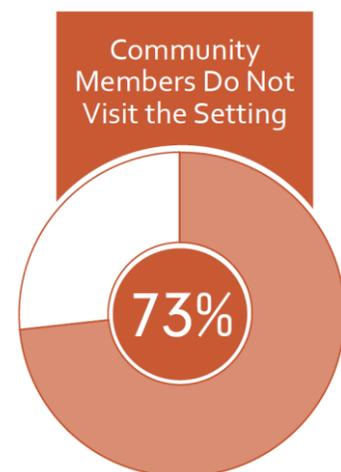
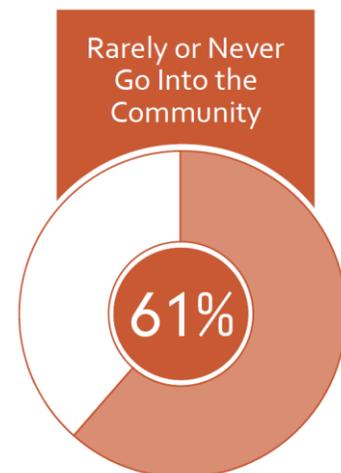
Non-residential settings include services where HCBS participants spend a large portion of their day. These settings generally include workshops, day programs and supported employment services. While we wish to emphasize that many of the non-residential service providers were clearly trying to provide quality services to individuals in their program, we found extensive compliance problems with many of these settings. Generally, we are concerned about the extent to which many non-residential

settings will need to evolve in order to be fully compliant with the rule. Specifically, we are concerned that this message has not been identified or conveyed by either DSPD or DMHF. While the rule does not eliminate facility-based programs, it does make clear that such programs must allow for meaningful community access.

The results of our survey indicated that many of the programs we visited were unable to provide daily or even weekly access to the community. Multiple programs were also physically isolated in industrial areas of town that did not allow for frequent interaction with the broader community. Additionally, many participants in these settings reported that they were not able to individualize their daily schedules and that community access was often dependent on participating in large group activities. Providers indicated that a lack of resources relating to transportation and staffing contributed to difficulty in this area. Without thoughtful, advanced planning to address these compliance problems, the DLC is concerned that many of these providers would be in danger of being dis-enrolled.

### Integration into the Community

- Just 43% of settings provided opportunities for regular meaningful activities in integrated community settings. This information was validated through consumer interviews in which 61% of respondents answered that they rarely or never go into the community.
- Only 43% of settings reported that they provide consumers with information about community activities outside of the setting. 28% of settings reported providing consumers with information about only disability specific events, and the remaining 28% reported providing no information about events outside of the setting.
- 100% of consumers reported being able to take time off for scheduled appointments as needed.
- 71% of settings maintained separate work areas for HCBS recipients and non-HCBS staff members.
- Although 57% of settings reported that they allow/encourage the community to visit the setting, 73% of consumers reported that individuals from the community do not visit while they are present in the setting.
- Over 50% of settings regularly discussed money management skills and how to increase an individual's rate of pay.



### **Individual Choice**

- 100% of consumers felt the setting reflected their needs and preferences.
- 71% of providers reported that all clients or groups of clients maintained the same schedule.

### **Individual Rights**

- 100% of consumers reported that staff regularly interacts with them.
- 100% of consumers reported they are comfortable discussing concerns with staff members.

### **Autonomy**

- 28% of settings had locked doors that prevent individuals' entrance to or exit from certain areas of the setting.
- 57% of consumers were not afforded the opportunity to choose with whom to do activities in the setting and were assigned only to be with a certain group of people.
- 71% of settings reported set meal times during which individuals could access food and snacks.

### **Choices about Services and Providers**

- 70% of consumers visited multiple settings when selecting providers, however, 30% of consumers reported a third party selected the setting for them such as a support coordinator, residential provider, or family member.

Although a majority of non-residential providers demonstrated compliance issues with the new settings regulations, we observed one facility-based day program that actively encouraged full access to the community for clients in the setting. The day program does so by:

- Offering multiple community activities each day
- Encourages individuals with disabilities to interact with those without disabilities
- Assists individuals in their day program to pursue competitive integrated employment
- Maintains an "open door" policy for visitors from the community
- Allows individuals to eat when and what they want, even if this is at an offsite location
- Reviews budgets and money management with clients each month
- Clients have individualized schedules that they helped to create

We believe this setting demonstrates that facility-based programs can achieve full compliance with the new rule by seeking out varied opportunities for individualized, community integration.

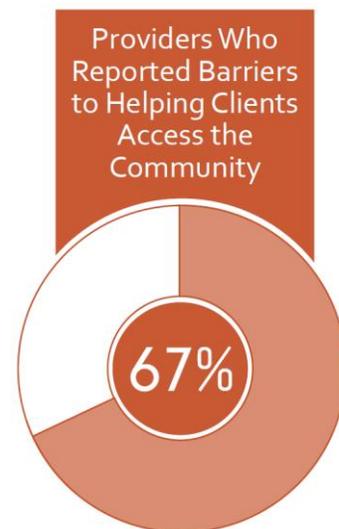
## Residential Findings

Residential settings include services such as group homes and apartments, supported living, and host homes. Generally we found that residential settings were mostly in compliance with the settings regulations with some notable exceptions. Most consumers reported individualized schedules, regular access to community events, and individuals felt the staff were friendly and responsive to their requests.

Areas of noncompliance primarily centered on the additional requirements for provider owned or controlled settings. Provider owned or controlled settings must meet additional conditions such as each individual has privacy in their sleeping unit including a bedroom with a lockable door, individuals sharing units have a choice of roommate in that setting, individuals have the freedom to furnish and decorate their bedroom, and individuals are able to have visitors of their choosing at any time.<sup>15</sup> Compliance with these provisions was problematic for several providers. We found that clients were often unable to choose their roommate, numerous consumers could not lock their bedroom doors, and two settings had policies that restricted friends and family from visiting at any time. Other areas of concern included restrictions on meal times and monitoring and supervision of internet and phone use that did not appear to be based on an assessed need. While these may at first appear to be small concerns, choices about how and with whom to spend time are essential to leading an independent life. These are the small decisions we make each day that form our tastes, interests, and lifestyles, and individuals with disabilities should have no fewer opportunities to decide where to eat a meal or when to have a friend visit.

### Integration into the Community

- 77% of consumers reported learning about community events and activities from staff members in the setting.
- 33% of consumers reported not being able to attend church, schedule appointments or visit with family and friends as they choose. One consumer reported not being able to attend religious activities due to a lack of staff. Other consumers responded that staff schedule all appointments on clients' behalf.
- 67% of providers reported barriers to assisting clients to come and go as they want. These barriers included a lack of staff and low reimbursement rates for transportation costs.



### Individual Choice

- 62% of consumers felt the setting reflected their needs and preferences.

- 67% of settings reported that consumers maintained individualized schedules. 33% of settings reported consumers were scheduled as part of a smaller group.
- 87% of consumers responded that staff ask them what they would like to do.
- 100% of consumers knew how to make a service request and 88% of consumers reported staff responded positively to their requests.

### **Individual Rights**

- One setting observed by DLC staff publicly displayed private health information such as schedules for physical therapy, prescriptions, and health needs.
- 45% of consumers reported not knowing how to or not feeling comfortable discussing concerns with their provider.
- 100% of consumers reported that staff regularly interacts with them, and 81% reported staff are friendly when they talk and interact.
- At least one setting did not have a formal grievance process.

### **Autonomy**

- 33% of settings reported maintaining a set meal time for all consumers.
- 100% of settings reported individuals can eat in a private place if they choose.
- 38% of consumers reported either restrictions or monitoring on the use of their private cell phones and internet.

### **Choices Regarding Services and Providers**

- 80% of consumers did not visit multiple providers when selecting a setting and 20% reported a third party selected the setting for them such as a provider or family member.

### **Provider Owned or Controlled Requirements**

- 50% of settings reported that roommates are chosen for individuals by a third party such as a treatment team, staff, or family member.
- 100% of consumers responded they did not get to pick their roommate, and one individual reported that he requested a new roommate and staff was non-responsive to this request.
- During our visits we observed that in 83% of settings bedrooms were decorated with personal items and décor.
- We found that 33% of settings had visitor policies that restricted when individuals could visit. Consistent with these findings, consumers at these settings reported not being able to have visitors at times of their choosing.

- We observed 33% of settings did not have lockable bedroom doors and in one setting we observed a setting had no door on at least one of the bedrooms in the home. Consistent with these observations, 58% of consumers reported they were not able to lock their bedroom door.

## Utah State Transition Plan Concerns

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The transition process is a critical opportunity to ensure compliance with the new settings rule and improve the quality of the HCBS service system. We have concerns that the State's approach to the transition process does not take advantage of this unique opportunity. Last March, the State submitted its transition plan to CMS for final approval. From March until October of 2015, the State made no measurable progress to assess settings, develop a more robust plan, or hold educational outreach sessions for consumers and providers—all things many other states have accomplished over the past year.

Utah's state transition plan, which is nine pages long, does not contain the level of detail necessary to evaluate the assessment and remediation measures that will be taken. For example, the transition plan states,

*"It has come to the State's attention that some setting types presumed to be Not Compliant or Not Yet Compliant by the State in the Preliminary Compliance Report may in fact be fully compliant with the HCBS Setting Rules."<sup>16</sup>*

However, the plan never explains what setting types now appear to be fully compliant or how that determination was made. Other examples include references to leveraging existing licensing and contract review schedules as a resource during the assessment process, without containing an explanation as to how these existing processes currently function.

The plan also fails to indicate that the State will publish the results of each stage of the provider assessment, or that it will publish the results of the State's internal assessment of the applicable standards, rules, regulations, and provider contracts. The public comment provisions of the new rule demonstrate CMS intended for this to be an open process with ample opportunities for individuals to provide feedback.<sup>17</sup> A plan that is lacking in detail and does not include expected dates for future public comment periods does not foster the type of public input that was intended by the rule.

Several states have transition plans that are much more detailed, measuring from 25 to approximately 90 pages.<sup>18</sup> The Michigan state transition plan includes a detailed explanation of how the state will conduct a settings assessment, including the steps the state took to develop a provider self-assessment tool, an explanation of the licensing processes used in the assessment, and the methodology and data sources used.<sup>19</sup> Many states are also further along in the transition process. For example, Michigan, Washington, Ohio, and Tennessee have all released the results of their settings assessment,<sup>20</sup> whereas Utah is only in the beginning stages of the State's settings assessment.

While Utah is not the only state in the early stages of a settings assessment, we have concerns about the amount of time that has passed during which it appears the state took no meaningful steps in the transition process. The State submitted its final transition plan to CMS on March 17, 2015, and took no significant action over the next several months while officials awaited feedback from CMS.<sup>21</sup> Given that the transition process must be completed by 2019, it is concerning that much of 2015 was not more effectively utilized to meaningfully advance the transition process.

## Assessment Concerns

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The DLC has concerns about the lack of opportunities for consumers to provide input into the assessment process. The State of Utah will use a provider self-assessment tool as a preliminary step in the assessment process.<sup>22</sup> The self-assessment allows a provider to submit a letter of support from the individuals it serves to demonstrate compliance<sup>23</sup>, but aside from this step there is no independent mechanism for consumers to provide input to the State. Although the State transition plan includes a measure to develop a participant experience survey to determine ongoing compliance after the assessment has concluded, we believe this measure must come much earlier in the transition process as our survey showed that consumer feedback was crucial to validating provider reports of compliance.

Of the 13 settings surveyed, we found that consumers at 10 settings provided us with information that conflicted with the provider's reported compliance. In some instances these conflicts called into question whole areas of compliance with the settings requirements. For example, at one setting a provider reported that they actively encourage individuals from the community to visit the setting. After interviewing multiple clients, each client responded that individuals from the community do not visit the setting. Another setting reported that individuals are afforded multiple opportunities for activities in the community. Yet, after interviewing several individuals the clients reported they did not leave the setting during the day. In some instances a setting had planned outings each week for consumers, and although the setting felt they were providing the level of integration required by the rule, consumer interviews revealed individuals desired to go into the community much more frequently than 2 to 3 activities each week. Without capturing consumer feedback in the assessment process across all settings, the State will be unable to accurately determine the service system's level of compliance.

We also have strong concerns the transition plan does not adequately describe the State's process to identify settings presumed to have the qualities of an institution or how the State will determine if the setting should be subjected to heightened scrutiny. The plan describes only a series of general assessment measures and indicates that these measures will be used to categorize compliant and non-compliant providers, including those settings presumed to have institutional qualities. Rather, the plan should include a detailed description of how the State will identify settings that isolate, what specific tools will be used to identify settings, and how the State will determine whether a setting should go through heightened scrutiny.

For example, the Michigan state transition plan has clearly outlined its process for how it will determine which settings are subject to heightened scrutiny.<sup>24</sup> Michigan's plan includes a flowchart to explain the qualities the state will use to identify settings that isolate, the process for collecting and submitting evidence for heightened scrutiny, and what types of evidence will be gathered.<sup>25</sup> All of these elements are noticeably absent from Utah's state transition plan.

It will not be enough to assume that our State will not have settings with institutional qualities. As we found during our survey, we observed 2 non-residential settings and 1 residential setting that had the effect of isolating individuals from the broader community. Out of a sample size of 13 settings, this amounts to 23% of providers surveyed. The 2 non-residential settings were both located in industrial areas, apart from the broader community. Staff and clients reported little to no community access or visitors from the community. The settings delivered multiple services on site or were co-located next to other non-residential settings controlled by the same provider. Portions of the settings were locked, prohibiting individual's entrance and exit into specified areas. The residential setting we observed lacked privacy in individual bedrooms, grouped a large number of residential units in one facility, did not contain personal décor in the living units, and multiple services were delivered onsite. Clients reported limited community access and difficulty scheduling appointments and visiting with family and friends.

These settings demonstrate several of the qualities put forth by CMS as settings that may have the effect of isolating individuals from the broader community.<sup>26</sup> The State must have a well-defined process for identifying these settings across all waivers. An explicit purpose of the new rule is to ensure that the State's limited HCBS dollars are spent only on settings that truly are home and community-based, and not on those settings with institutional qualities. Therefore, the State must take additional efforts to define a clear heightened scrutiny process, or it risks improperly allocating HCBS funding for settings that do not meet the settings requirements.

## Systemic Barriers to Compliance

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Interviews with providers revealed that current policies, reimbursement rates, and provider contracts through DSPD may be a barrier to compliance with the new settings rule. However, it is unclear from the transition plan how the State intends to address these barriers.

For example, the open-ended request for proposals (RFP) through DSPD includes several measures that are contradictory to the settings rule. The residential habilitation supports and supported living descriptions of the RFP include a provision that contractors must have policies and procedures establishing the amount of time family and friends may stay as overnight guests.<sup>27</sup> Yet, the provider owned or controlled provisions of the settings rule states that individuals should have the ability to have visitors at any time.<sup>28</sup> Further, these descriptions also address access to community services, stating that the contractor shall assist clients in accessing community services such as finding housing, applying for food stamps, and obtaining Social Security benefits. This provision fails to mention the HCBS requirement that a setting support full access to the greater community, including opportunities to seek employment and work in competitive integrated settings, engage in community

life, control personal resources, and receives services in the community to the same degree of access as individuals not receiving HCBS.<sup>29</sup> As the RFP sets the expectations and requirements for HCBS service providers, this document should accurately reflect the community access provisions required by the new settings rule.

DSPD also uses a process to help individuals select a provider called an "Invitation to Submit Offer to Provide Services" (ISO). The ISO process is initiated by completing a form that describes the individual's needs. The form is completed by DSPD or the individual's support coordinator and is then sent to providers. Providers wishing to submit an offer to provide these services must then submit a written provider declaration of interest.<sup>30</sup> Out of the 13 settings surveyed 53% of providers responded that individuals are referred to their program through the ISO process. In our understanding of the ISO process it does not seem to comport with the settings requirements regarding setting selection and choice. The rule requires a setting be selected by an individual from a range of options, including non-disability specific settings.<sup>31</sup> However, it appears the ISO is sent only to HCBS providers and does not include an option for non-disability specific settings. Further, the ISO process requires a provider to affirmatively respond. Should only one provider respond, the client would not have a range of settings to choose from as required by the rule. The rule also requires a setting to facilitate individual choice regarding services and supports, and who provides them.<sup>32</sup> Yet, the ISO form is completed by a support coordinator and sent to providers for a response. This largely excludes the individual from providing input on the type of supports needed or which providers to send the form to.

Our interviews with providers also revealed that DSPD reimbursement rates are frequently a barrier to community access. Many providers noted that transportation rates are very low which can make it difficult for them to help clients access the community. Over half of providers also commented that the pay rate for direct care staff makes it difficult to attract and retain staff. This is unsurprising as a 2015 report by the Office of the Legislative Auditor General found that compensation and retention of direct care staff needs improvement.<sup>33</sup> The report found that starting wages in Utah are below the national average, which has in part led to high annual turnover rates.<sup>34</sup> Providers noted that maintaining appropriate staffing levels affects their ability to support individuals wishing to access the community. Other providers noted that the declining hourly reimbursement rate<sup>35</sup> for supported employment makes it difficult to serve individuals with more intensive needs. Similar concerns were noted by supported living providers. One staff member commented that providing services in the community requires significant time and resources that are not reimbursed, and that the more integrated the services are the more out of pocket expenses must be paid by the provider.

It is presently uncertain from the transition plan how the State intends to work with DSPD to address these systemic barriers. Although DSPD is listed as a general stakeholder on the transition plan, it is unclear if the State intends to evaluate DMHF and DSPD policies, contracts, provider manuals, regulations and statutes in its internal assessment. Moreover, we are concerned there does not appear to be more collaboration between DSPD and DMHF to evaluate what additional resources or legislative funding will be required to fully implement the new settings regulations and set forth a plan to address barriers such as low reimbursement rates.

## Person-Centered Planning

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The HCBS settings rule includes new requirements for the person-centered planning process. While states have 5 years to comply with the settings regulations, standards for the person-centered planning process are currently in effect. The new person-centered planning regulations are intended to help an individual “construct and articulate a vision for the future, consider various paths, engage in decision-making and problem solving, monitor progress, and make needed adjustment to goals and HCBS in a timely manner.”<sup>36</sup> The DLC conducted a review of current DSPD policies and found many instances where the policies do not comply with the new regulations regarding person-centered planning. Notable examples include:

- The new regulations require the person with a disability to lead the process of making the plan,<sup>37</sup> but DSPD policy only requires input from the person and their team to guide the PCP process.<sup>38</sup> The regulations also require that the time, place and location are chosen by the individual.<sup>39</sup> Current DSPD policies do not include such a requirement.
- The new rule emphasizes informed consent on the part of the individual; the planning process “provides necessary information and support to ensure that the individual directs the process to the maximum extent possible, and is enabled to make informed choices and decisions.”<sup>40</sup> Information needs to be provided in an accessible manner so that the person with a disability can understand it.<sup>41</sup> While DSPD policy contemplates principles of informed choice,<sup>42</sup> it does not require information to be presented in an accessible manner.<sup>43</sup>
- The new rule requires person-centered service plans to include assurances that the person will receive services of his or her choice in integrated community settings as required by the rule.<sup>44</sup> DSPD policies as currently written make no such provision.
- The new regulations state that there must be clear conflict of interest guidelines for participants in the person-centered planning process<sup>45</sup> and that unless absolutely necessary, the same providers who are going to be providing services should not be creating the plan or directing the process.<sup>46</sup> DSPD policies do not include conflict of interest provisions and do not explain the prohibition on current or intended providers creating the plan or guiding the process.

The new person-centered planning rules have the potential to assist the State in providing care that promotes independence, well-being and autonomy for individuals receiving services, and to ensure that HCBS services received by individuals reflects choice in an integrated setting. Current versions of State policies do not comply with the requirements of the new CMS regulations regarding person-centered planning. From our review of state transition plan materials it does not appear the State has a formal process to address these discrepancies. We would expect the State to swiftly make the changes necessary to ensure compliance with the person-centered planning regulations.

## Conclusion and Recommendations

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The results of our assessment showed that few settings within the HCBS service system are fully compliant with the new settings requirements. Based on our observations we expect the State's assessment will similarly show that most providers will need to develop a remediation plan. Although many providers will need to make only small changes, our assessment showed that some providers will need to significantly alter the way in which services are provided, particularly in non-residential settings.

As we found during our assessment, these changes cannot be imposed on providers alone. The State will need to carefully assess all aspects of the service delivery system, including those functions performed by DMHF and DSPD. The DLC is calling on DMHF and DSPD to work more closely together and lead a collaborative effort to review the service system for compliance with the settings rule. It has been our observation that collaboration between these agencies has been fleeting if not completely absent. Without purposeful collaboration, there will be no meaningful discussion regarding which specific areas of the system need immediate attention, and how best to support providers who may have difficulty bringing their program into compliance.

Thus far, it has appeared that the State's approach has been to assume compliance in hope of making only small tweaks or changes to the system at large. Unfortunately, in our observations, this will not be sufficient and immediate action is needed. As the results of our survey indicate, there are several areas of the system that will require some degree of change ranging from small changes to a complete overhaul in order to become compliant. Given the lack of meaningful progress in 2015, the DLC is concerned that if the current pace continues, portions of the provider system will not be compliant by 2019. Such a result would not only be troubling for providers who may be dis-enrolled, but tragic for the HCBS recipients and their families who would be left searching for appropriate services within a notably depleted service system. In an effort to avoid such a result and to provide the highest quality services for Utahns with disabilities, we are hopeful that 2016 will yield significant progress towards compliance.

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<sup>1</sup> Cindy Mann, *CMCS Informational Bulletin*, Center for Medicaid & Chip Services, Jan. 10 2014, <http://www.medicaid.gov/federal-policy-guidance/downloads/cib-01-10-14.pdf>.

<sup>2</sup> 79 Fed. Reg. 2948, 2451 (Jan. 16, 2014) ("Along with our overarching goal to improve Medicaid HCBS, we seek to ensure that Medicaid is supporting needed strategies for states in their efforts to meet their obligations under the ADA and the Supreme Court decision in *Olmstead v. L.C.*, 527 U.S. 581 (1999)").

<sup>3</sup> *Olmstead v. L.C.*, 527 U.S. 581, 607 (1999).

<sup>4</sup> *Id.*

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HCBS SETTINGS RULE  
*An Opportunity for Inclusion*

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<sup>5</sup> See Utah State Plan Under Title XIX of the Social Security Act Medical Assistance Program § 3 - Services: General Provisions, <http://www.health.utah.gov/medicaid/stplan/Section3.pdf>.

<sup>6</sup> See Utah Home and Community Based Services (HCBS) Waiver Program, <http://health.utah.gov/ltc/>.

<sup>7</sup> UTAH DEPARTMENT OF HUMAN SERVICES, DIVISION OF SERVICES FOR PEOPLE WITH DISABILITIES ANNUAL REPORT 2015 19 (2015) [http://dspd.utah.gov/pdf/DSPD\\_Annual\\_Report\\_FY2015.pdf](http://dspd.utah.gov/pdf/DSPD_Annual_Report_FY2015.pdf).

<sup>8</sup> 42 C.F.R. §§ 441.301(c)(4)(i)-(v).

<sup>9</sup> 42 C.F.R. § 441.301(c)(5)(v).

<sup>10</sup> *Id.*

<sup>11</sup> 42 C.F.R. § 441.301(c)(6)(ii).

<sup>12</sup> 42 C.F.R. § 441.301(c)(6)(iii).

<sup>13</sup> UTAH DEPARTMENT OF HUMAN SERVICES, *supra* note 7, at 15.

<sup>14</sup> CMS, *Fact Sheet: Summary of Key Provisions of Home and Community-Based Services (HCBS) Settings Final Rule*, Jan. 10, 2014, <http://www.medicare.gov/Medicare-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Supports/Home-and-Community-Based-Services/Downloads/HCBS-setting-fact-sheet.pdf>.

<sup>15</sup> 42 C.F.R. §§ 441.301(c)(4)(vi)(A)-(F).

<sup>16</sup> DRAFT Utah HCBS Setting Transition Plan, <http://health.utah.gov/ltc/hcbstransition/Files/Utah%20HCBS%20Setting%20Transition%20Plan%20December%202015.pdf>.

<sup>17</sup> 42 C.F.R. § 441.301(c)(6)(iii).

<sup>18</sup> For example the Georgia plan is 25 pages, the Michigan plan is 90 pages, the Idaho plan is 60 pages, and the South Dakota plan is 64 pages.

<sup>19</sup> Michigan's Statewide Transition Plan for Home and Community-Based Services, [http://www.michigan.gov/documents/mdhhs/Revised\\_Statewide\\_Transition\\_Plan\\_V2.o\\_Final\\_Draft\\_508595\\_7.pdf](http://www.michigan.gov/documents/mdhhs/Revised_Statewide_Transition_Plan_V2.o_Final_Draft_508595_7.pdf).

<sup>20</sup> Michigan's Statewide Transition Plan for Home and Community-Based Services, [http://www.michigan.gov/documents/mdhhs/Revised\\_Statewide\\_Transition\\_Plan\\_V2.o\\_Final\\_Draft\\_508595\\_7.pdf](http://www.michigan.gov/documents/mdhhs/Revised_Statewide_Transition_Plan_V2.o_Final_Draft_508595_7.pdf), Washington State's Revised Statewide Transition Plan for New HCBS Rules, <https://www.dshs.wa.gov/sites/default/files/ALISA/stakeholders/documents/HCBS/Washington%20State--Transition%20Plan%20for%20New%20HCBS%20Rules--Revised%201-14-15.pdf>, Ohio's HCBS Transition Plan, <http://www.healthtransformation.ohio.gov/LinkClick.aspx?fileticket=ACuNUmAvZ6E%3d&tabid=125>, Tennessee Home and Community-Based Services Settings Rule Statewide Transition Plan, <https://tn.gov/assets/entities/tenncare/attachments/TNProposedStatewideTransitionPlanCleanVersion.pdf>.

<sup>21</sup> The transition plan shows during this time the State took steps to develop a provider self-assessment and compliance tools and began a review of the relevant standards, rules, regulations, and provider contracts.

<sup>22</sup> DRAFT Utah HCBS Setting Transition Plan, <http://health.utah.gov/ltc/hcbstransition/Files/Utah%20HCBS%20Setting%20Transition%20Plan%20December%202015.pdf>.

<sup>23</sup> Non-Residential provider Self-Assessment Tool Instructions, <http://health.utah.gov/ltc/hcbstransition/Files/Self-Assessment%20Instructions%20NonResidential.pdf>.

<sup>24</sup> Michigan State Transition Plan, [http://www.michigan.gov/documents/mdhhs/Revised\\_Statewide\\_Transition\\_Plan\\_V2.o\\_Final\\_Draft\\_508595\\_7.pdf](http://www.michigan.gov/documents/mdhhs/Revised_Statewide_Transition_Plan_V2.o_Final_Draft_508595_7.pdf).

<sup>25</sup> *Id.*

<sup>26</sup> CMS, *Guidance on Settings that have the Effect of Isolating Individuals Receiving HCBS from the Broader Community*, <https://www.medicare.gov/medicaid-chip-program-information/by-topics/long-term-services-and-supports/home-and-community-based-services/downloads/settings-that-isolate.pdf>.

<sup>27</sup> Division of Services for People with Disabilities, RFP # DHS90548, Open-Ended Request for Proposals (2015).

<sup>28</sup> 42 C.F.R. § 441.301(c)(4)(vi)(D).

<sup>29</sup> 42 C.F.R. § 441.301(c)(4)(i).

<sup>30</sup> Division of Services for People with Disabilities, Form ISO 1-6, Invitation to Submit Offer to Provide Services (ISO) (2015).

<sup>31</sup> 42 C.F.R. § 441.301(c)(4)(ii).

<sup>32</sup> 42 C.F.R. § 441.301(c)(4)(v).

<sup>33</sup> OFFICE OF THE LEGISLATIVE AUDITOR GENERAL, REPORT ILR 2015-A: A LIMITED REVIEW OF PROVIDER RATES FOR THE DIVISION OF SERVICES FOR PEOPLE WITH DISABILITIES 3 (2015), <http://le.utah.gov/interim/2015/pdf/00001775.pdf>.

<sup>34</sup> *Id.* at 3-4.

<sup>35</sup> Division of Services for People with Disabilities, Form ISO 1-6, Invitation to Submit Offer to Provide Services (ISO) (2015).

<sup>36</sup> Section 2402(a) of the Affordable Care Act – Guidance for Implementing Standards for Person-Centered Planning and Self-Direction in Home and Community-Based Services Programs, <http://www.acl.gov/Programs/CIP/OCASD/docs/2402-a-Guidance.pdf>.

<sup>37</sup> 42 C.F.R. § 441.301 (c)(1).

<sup>38</sup> “Input from the person and their team should guide and direct this process,” Division of Services for People with Disabilities, Policy 1.9, Person-Centered Planning (2004).

<sup>39</sup> 42 C.F.R. § 441.301 (c)(1)(iii).

<sup>40</sup> 42 C.F.R. § 441.301 (c)(1)(ii).

<sup>41</sup> 42 C.F.R. § 441.301 (c)(1)(iv).

<sup>42</sup> Division of Services for People with Disabilities, Policy 1.9, Person-Centered Planning (2004).

<sup>43</sup> 42 C.F.R. § 441.301 (c)(1)(iv).

<sup>44</sup> 42 C.F.R. § 441.301 (c)(2)(i).

<sup>45</sup> 42 C.F.R. § 441.301 (c)(1)(v).

<sup>46</sup> 42 C.F.R. § 441.301 (c)(1)(vi).

## Our Mission

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*As Utah's federally designated Protection and Advocacy (P&A) Agency, the Disability Law Center works to enforce and strengthen laws that protect the opportunities, choices, and legal rights of people with disabilities in Utah.*



205 North 400 West  
Salt Lake City, Utah 84103  
800.662.9080 | fax 801.363.1347



[disabilitylawcenter.org/hcbs](https://disabilitylawcenter.org/hcbs)