

Appendix 10



**HCBS Settings Surveys Findings:
Maryland Residential Provider, Participant/Caregiver,
and Case Manager/Supports Planner**

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Executive Summary

To assist the Maryland Department of Health and Mental Hygiene (DHMH) write its transition plan for the Centers for Medicare and Medicaid Services (CMS) regarding Home and Community-Based Service Settings in Maryland, The Hilltop Institute developed and administered three surveys. The focus of this report is on the first two—the provider and participant surveys—while the majority of the analysis of the third survey is included in the appendix. The purpose of the provider and participant surveys was to obtain an initial understanding of home and community based service delivery and to identify areas in need of further assessment. Because CMS had provided more guidance with respect to residential services under the Final Rule, providers of and participants in residential services were the target groups.

The Hilltop Institute developed the survey instruments after reviewing the guidance from CMS and several other states' instruments. Given the time limitations and goal of the surveys, one provider instrument and one participant survey were used across waiver groups. In the future, it may prove beneficial to develop more refined tools that account for differences between waiver populations while still assessing the required Final Rule criteria. It is also important to note while efforts were made to increase the number of responses for each survey, this impacted the representativeness of the responses; as such these results are not representative of all consumers and providers across the state.

The survey analysis consisted of basic descriptive statistics, primarily frequency distributions. Comparisons were made between the participants and providers, and between participants and case managers when applicable. Each survey allowed for comments to be made that were analyzed for similarities and trends.

Findings of note included 10.5 percent of providers indicating their setting was located in an institutional inpatient treatment setting and 30.6 percent of providers indicating their setting was near other settings for people with disabilities that they run. In addition, 59.1 percent of providers indicated they only serve individuals with disabilities. These findings need to be further investigated. Other areas that appear to need further evaluation are an individual's control of personal resources, transportation as it affects community access, signing a lease, choice of living arrangement, access to food at any time, and privacy issues (entrance door being locked, for example).

HCBS Settings Surveys Findings: Maryland Residential Provider, Participant/Caregiver, and Case Manager/Supports Planner

Introduction

The Hilltop Institute was asked by the Maryland Department of Health of Mental Hygiene (DHMH) to develop three surveys to gather initial information regarding home and community-based services (HCBS) settings in Maryland. The three surveys requested included a residential provider survey, a participant survey, and a case manager survey. The intent of the first two surveys was to broadly assess the current state of HCBS settings as they relate to the HCBS settings criteria set forth by the Centers for Medicare and Medicaid Services (CMS) on January 16, 2014.¹ The intent of the third survey—the case manager survey—was to begin to gauge the current state of person-centered planning in Maryland since those criteria went into effect on March 17, 2014. This report presents the methodology and results for the three surveys, limitations of the study, and suggestions for future assessments. This report focuses on the results of the provider and participant surveys, with only brief comparisons provided from the case manager survey. A summary results table and brief discussion of the case manager survey is presented in Appendix A.

Methodology

To develop the provider, participant, and case manager instruments, Hilltop reviewed questions from CMS's exploratory questions document and several other states' instruments, including Nevada's residential settings self-assessment form, Tennessee's residential provider self-assessment form and person-centered planning assessment, and Kansas's HCBS compliance survey for providers.² To further assist in developing the participant instrument, Tennessee's individual experience assessment tool and Indiana's transition plan were also reviewed.

Hilltop focused on residential services for the provider and participant surveys because CMS provided the most guidance on those criteria in the Final Rule. Nevada and Tennessee used the same approach in which only residential providers conducted self-assessments. Providers also filled out one survey for each type of residential setting (for example, assisted living or residential habilitation), as opposed to filling out a survey for each residential site.³ In addition, because the Final Rule also outlined criteria for the person-centered planning process and the required content of person-centered plans that were already supposed to be implemented, the state decided to do a brief survey of case managers on that specific criteria as well.

¹ <http://www.medicaid.gov/medicaid-chip-program-information/by-topics/long-term-services-and-supports/home-and-community-based-services/home-and-community-based-services.html>

² The assessment was online and the link is no longer available, but Hilltop does have a printed copy of the assessment.

³ Nevada and Tennessee instructed providers to fill out the self-assessment form for each site/address, while Kansas instructed providers to fill out one survey for each type of setting.

About half of the survey questions on the provider and participant surveys focused on the additional criteria CMS set forth regarding provider-owned or controlled residential settings. The rest of the questions related to the broad home and community based settings criteria. Answer choices were limited to yes/no in order to gain an initial understanding of HCBS settings, and how providers and participants viewed their settings and their services. While the provider and participant surveys differed, the same survey was used for each group across the waivers because the same Final Rule criteria applied regardless of program. All three surveys were given to various stakeholder groups to review and, when appropriate, changes were made to the surveys based on their feedback.

The survey instruments were web-based, but respondents could request a paper copy of each survey. Three different letters (one for residential providers, one for residential consumers, and one for case management agencies) were drafted by DHMH that described the purpose of the survey for that group, provided the web link for the relevant survey, contact information to request a paper copy of the survey, and contact information for Hilltop regarding any questions about the survey. Hilltop developed the mailing lists for the residential providers, residential participants, and case management agencies using Medicaid Management Information Systems (MMIS) claims data. Because the focus was on residential services, only HCBS waivers and/or state programs that offered them were included (Maryland's Autism Waiver, Traumatic Brain Injury Waiver, Home and Community-Based Options Waiver, and the Community Pathways Waiver). Hilltop pulled providers and participants with residential claims between June-August 2014, and the case management agencies for those participants was March–August 2014. The mailing list included 553 residential providers, 6,678 participants receiving residential services, and 23 case management agencies. Hilltop received approximately 63 calls regarding the participant survey, 15 calls regarding the provider survey, and 1 call regarding the case manager survey. All requests Hilltop received for paper copies were either delivered to DHMH staff in person or via fax to ensure confidentiality.

To illicit as many responses as possible, the links for all the surveys were posted on both DHMH's website⁴ and the Developmental Disabilities Administration's (DDA's) website.⁵ DHMH also posted printable copies on its website. The surveys were discussed at eight public information sessions in early October 2014⁶ and during a webinar on October 21, 2014. There was a significant jump in all survey responses on October 21, possibly due to discussing it during the webinar, but more likely due to an email sent to employees from Service Coordination, Inc. regarding completing the surveys. It is important to note that many participants who filled out the survey were not receiving residential services even though the original mailing only went out to residential participants. Because individuals outside of the mailing lists were encouraged to complete the surveys, the response rates for the participant and provider surveys should be viewed with caution. This also impacted the representativeness of the survey responses. Those who are more active and have stronger opinions (in any direction) may be over represented. A concern in survey research is if those

⁴ <https://mmcp.dhmf.maryland.gov/waiverprograms/SitePages/Community%20Settings%20Final%20Rule.aspx>

⁵ <http://dda.dhmf.maryland.gov/SitePages/HCBS.aspx>

⁶ There were two information sessions on each of the following dates and locations: 10/6/14 Bowie, MD; 10/7/14 Hagerstown, MD; 10/14/14 Cambridge, MD; and 10/15/14 Columbia, MD.

respondents who take the time to complete the survey are somehow different from the population at large. Finally, because only case management agencies were sent a letter, but all case managers at each agency were encouraged to fill out the survey, it is not possible to calculate a response rate for the case manager survey.

The provider survey yielded a response rate of 25.5 percent, with 141 responses. There were 646 participant responses, resulting in a response rate of 9.7 percent. There were 187 case manager responses, but as noted earlier, it is not possible to determine the response rate. The response rate for the participant survey appears to be low. This may be due to the fact that it was an online survey, which typically yields a lower response rate, or that it was voluntary, with no incentives offered for completion. Additional limitations of the surveys are addressed at the end of the document.

Statistical Program for the Social Sciences (SPSS) was used to conduct the quantitative analysis, which consists of basic descriptive statistics, primarily frequency distributions. Estimates of the number of providers affected are given when applicable, with a reminder that they are estimates and should be viewed with caution given the limitations of the survey. Summary tables are presented in the results section.

At the end of each survey was a comment section. There were 152 comments from participants, 32 from providers, and 43 from case managers. Comments were analyzed for similarities and trends.

Results

Providers

Location of Settings and Type of People Served

As noted earlier, 141 providers completed the provider survey. Of these, 47.8 percent (n=65) were assisted living providers and 52.2 percent (n=71) were residential habilitation providers. Five providers failed to answer this question. Several questions were asked about the physical location of their settings, as well the type of people served at the settings. Because providers were answering only on the type of setting and not answering surveys based on each site, they were asked to answer what was typical of most of the settings of that type (i.e. assisted living or residential habilitation). The questions were based on following HCBS Final Rule criteria:⁷

1. Settings that are NOT home and community-based include nursing facilities, institutes for mental diseases (IMDs), intermediate care facilities for individuals with intellectual disabilities (ICFs/IID), and hospitals.

⁷ <http://www.medicaid.gov/medicaid-chip-program-information/by-topics/long-term-services-and-supports/home-and-community-based-services/home-and-community-based-services.html>. Please note, not all the HCBS criteria are listed; only those relevant to the questions asked are noted.

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2. Settings are PRESUMED NOT to be home and community-based if the setting has the effect of isolating individuals from the broader community of individuals not receiving Medicaid HCBS. CMS’s additional guidance regarding settings that isolate is as follows:
- a. The setting is specifically for people with disabilities, and often even people with a certain type of disability.
 - b. The individuals in the setting are primarily or exclusively people with disabilities and on-site staff provides many services to them.
 - c. People in the setting have limited, if any, interaction with the broader community.
 - d. Examples of settings that isolate include residential schools and multiple settings co-located and operationally related (i.e., operated and controlled by the same provider) that congregate a large number of people with disabilities together and provide for significant shared programming and staff.

Below, Table 1 shows the results of these questions.

Table 1. Provider Residential Setting Location and People Served

Residential Settings Questions	Yes	
	Percentage (Frequency)	N
Setting is in a publicly or privately owned facility that provides inpatient institutional treatment	10.5% (12)	114
Setting is near other settings that the providers run for people with disabilities	30.6% (34)	111
Setting is located in the same building as an educational program or school	1.7% (2)	120
Private residences are near the setting	94.9% (111)	117
Other businesses are near the setting	62.9% (73)	116

Residential Settings Questions	Yes	
	Percentage (Frequency)	N
Type of People Served at the Setting		115
Only people with disabilities	59.1% (68)	
The majority of the people have disabilities	26.1% (30)	
Very few people have disabilities	14.8% (17)	

Table 1 illustrates some areas of potential concern given the HCBS Final Rule criteria. CMS notes that settings that are in a publicly or privately owned facility that provide inpatient institutional treatment fail to meet the HCBS criteria. Accordingly, 10.5 percent of residential providers responded that their settings are located in these facilities. While seemingly a small percentage, if this is applied to all residential waiver providers to estimate the impact, it means roughly 58 residential providers will no longer be permitted to provide services in the facilities they are currently in. For settings that are presumed to not be home and community-based, 30.6 percent of residential providers indicated that their setting is near other settings run by the provider for people with disabilities. By this estimate, 169 residential providers would be subject to heightened scrutiny, meaning additional evidence is needed to determine if the setting is institutional or home and community-based. Additional estimates for settings subject to heightened scrutiny include the two providers (1.7 percent) who indicated the setting was located in the same building as an educational program or school. Finally, 59.1 percent of providers indicated they served only people with disabilities, and 26.1 percent of providers answered that the majority of people that they serve have disabilities.

Two remaining questions—if the setting is near other residences and if the setting is near other businesses—were used as indicators to help determine the level of interaction between participants and the broader community. The majority (94.9 percent) of providers indicated the setting is near other residences, and 62.9 percent indicated the setting was near other businesses. Short of specific guidance from CMS, it appears the state should focus on other more tangible criteria with respect to settings subject to heightened scrutiny.

Control Personal Resources

The HCBS Final Rule also stipulates that the setting should provide opportunities for participants to control personal resources. The providers were asked a series of questions regarding this issue and the results are presented in Table 2.

Table 2. Providers on Participants Managing Finances

Financial Questions	Percentage (Frequency)
Individuals are allowed to have their own bank accounts that they manage (N=116):	
Yes	77.6% (90)
No	3.4% (4)
Individuals do not have bank accounts	19.0% (22)
Individuals are required to have a representative payee to live in the setting (A representative payee is an individual or organization named by the Social Security Administration to handle another's social security benefits.) (N=106):	
All individuals must have representative payee	29.2% (31)
Only some individuals must have representative payee	34.0% (36)
No individuals are forced to have a representative payee	36.8% (39)

The results indicate that this is an area that may need to be addressed to ensure providers are encouraging participants to achieve a suitable level of control over their personal finances. Both questions were indicators for the criteria that participants be supported in controlling their personal resources. Of providers, 77.6 percent indicated that participants are allowed to have bank accounts that they manage themselves, and 19.0 percent indicated that participants did not have bank accounts at all. With respect to representative

payees, 29.2 percent of providers responded that all participants must have a representative payee to live in their setting, 34.0 percent indicated at least some individuals must have representative payees, and 36.8 percent noted that no individuals are forced to have a representative payee.

While it is a justified concern that not all participants have the necessary skills to manage their finances, this must be weighed against preconceived ideas and misconceptions. At a minimum, blanket policies that force representative payees on all participants as a condition of service need to be reviewed.

Participants

A total of 646 participants responded to the survey. Of the 646 participants, 71 indicated they lived in an assisted living unit, 186 indicated they lived in a group home/alternative living unit, 205 indicated it was neither an assisted living unit or a group home/alternative living unit, 6 indicated they did not know, and 178 did not answer the question. Results specific to participants are presented below, followed by comparisons of participants' answers to those of providers and case managers on the same questions to see where there are similarities and where there are differences.

Employment, Engagement in Community Life, and Control of Personal Resources

The Final Rule criteria state that settings should provide opportunities for participants to work in competitive, integrated environments, engage in community life, and control personal resources. Competitive employment refers to one earning at least the minimum wage or wages similar to non-disabled persons in the same job and paid directly by the employer. Integrated employment is when individuals with severe disabilities working in an environment where the majority of employees do not have disabilities.⁸

Table 3 addresses several employment indicators to assess the criteria set forth in the Final Rule, as well as community engagement and control of personal finances.

Table 3. Participant Employment Issues, Engagement in Community Life, and Finances

Question	Percentage (Frequency)	N
Participants indicating they are employed outside of the home	38.7% (241)	622

⁸ <http://www.dol.gov/odep/topics/WIOA.htm>

Question	Percentage (Frequency)	N
Participants' description of the type of people they work with		198
Most of them have disabilities	32.3% (64)	
Some of them have disabilities	33.3% (66)	
No one else has disabilities except me	15.7% (31)	
Don't know	18.7% (37)	
Participants indicating they get a paycheck from their employer	87.7% (143)	163
Participants indicating they get paid minimum wage or higher	64.9% (109)	168
In charge of my own banking (I manage my own checking and/or savings account)		471
Yes	25.5% (120)	
No	60.7% (286)	
I do not have a bank account	13.8% (65)	
How many days per week do you get to the community? (For example, to go shopping, attend religious services, eat at restaurants, etc....)		529
0 days	9.1% (48)	
1-2 days	34.8% (184)	

Question	Percentage (Frequency)	N
3-4 days	25.0% (132)	
5-7 days	31.2% (165)	

Of those participants surveyed, 38.7 percent indicated they are currently employed outside of the home. Maryland's labor force participation among people with disabilities is therefore higher than the national average of 20.0 percent in October of 2014.⁹ When those participants who indicated they were working were also asked to describe the type of people they work with, 15.7 percent responded that they were the only person who had disabilities, which indicates that there is still work to be done to achieve an integrated employment setting, 64.9 percent of those working stated they earn the minimum wage or higher, again indicating that there is work to be done to obtain a competitive employment setting. It is also important to note that 87.7 percent of participants reported getting their paycheck from their employer, an important indicator of competitive employment.

Controlling personal resources is another criterion set forth in the Final Rule. The question “Are you in charge of your banking? (For example, you manage your checking and/or savings account.)” was used as an indicator. Among participants who responded to the question, 25.5 percent indicated they were in charge of their banking, while 60.7 percent stated they were not in charge of their banking, and 13.8 percent indicated the question was not applicable to them because they did not have a bank account. This question is slightly different from the providers’ question, which asked if individuals were allowed to have their own bank accounts that they manage, which may explain why the providers’ percentage was so much higher at 77.6 percent. This indicates participants are *allowed* to have their own bank accounts that they manage, not necessarily that they are actually managing their own bank accounts.

The question “How many days per week do you get to the community? (For example, to go shopping, attend religious services, eat at restaurants, etc....)” was used as an indicator for level of engagement in community life. While there is no exact number of days per week that is indicative of engagement since it should be based on personal choice, 9.1 percent of respondents reported that they had not gone to the community to shop, attend a religious service, eat at a restaurant, etc.

⁹ <http://www.dol.gov/odep/>

Providers and Participants

Involvement and Access to the Community, and Rights of Privacy, Respect, and Control

Providers and participants were asked a series of questions regarding involvement and access to the community, and the participants' rights of privacy, respect, and control. The specific criteria the questions were based on are as follows:

1. The HCBS setting provides opportunities to seek employment and work in competitive integrated settings, engage in community life, and control personal resources.
2. The HCBS setting ensures an individual's rights of privacy, dignity, respect, and freedom from coercion and restraint.

Tables 4 and 5 display the results of these questions.

Table 4. Involvement, Access to the Community, and Employment Support

Question	Yes			
	Participants		Providers	
	Percentage (Frequency)	N	Percentage (Frequency)	N
Information is given to participants about community activities by service providers	71.9% (387)	538	97.3% (110)	113
Access to public transportation is available	48.2% (253)	525	72.2%* (78)	108
Staff are available to take participants to non-health related activities	68.1% (357)	524	87.1% (101)	116
Participants indicate they received help getting their job	57.4% (112)	195	62.4% (68)	109

*exact wording: "Is public transportation accessible from the setting?"

Question	Yes			
	Participants		Providers	
	Percentage (Frequency)	N	Percentage (Frequency)	N

Table 5. Rights of Privacy and Respect

Question	Yes			
	Participants		Providers	
	Percentage (Frequency)	N	Percentage (Frequency)	N
Participants are able to get assistance from staff in private	83.0% (382)	460	96.6% (113)	117
Information about filing a complaint is posted in an easy-to-find location	54.0% (236)	437	86.0% (98)	114
Participants are able to make a complaint without providing their name	62.9% (261)	415	94.8% (110)	116
Participants are spoken to in a respectful manner	91.6% (424)	463	100.0% (117)	117

In Table 4, 71.9 percent of participants indicated that information about community activities is given to them from their service providers, while 97.3 percent of providers indicated this information is given to participants. With respect to access to transportation, 48.2 percent of participants indicated that they are able to access public transportation, while 72.2 percent of providers indicated there is public transportation accessible from their setting. Providers and participants differ with respect to staff being able to take participants to non-health related activities, but they are similar in their reporting of employment help provided to participants.

As Table 5 shows, participant and provider responses are similar for one question regarding privacy and respect but vary for the others. Regarding speaking to participants in a respectful manner, participants and providers are relatively close, at 91.6 percent and 100.0 percent, respectively. However, 83.0 percent of participants reported being able to receive assistance from staff in private while 96.6 percent of providers reported that this is done. With respect to being able to file complaints, only 54.0 percent of participants indicated the process was posted in an easy-to-find location, compared to 86.0 percent of providers. In terms of filing a complaint

without providing one's name, 62.9 percent of participants indicated this was possible, compared to 94.8 percent of providers. These differences may be due to providers reporting policy and the participants reporting based on their perception of what is occurring in the field.

Rights of Privacy, Choice, and Independence in the Residential Setting

Providers and participants were asked a series of similar questions regarding the criteria specific to provider-owned or controlled residential settings. Participants indicating they did not live in an assisted living unit or a group home/alternative living unit (N=205) or who did not answer the question (N=178) were excluded from the analysis, leaving 263 participants.

The criteria the survey questions were based on are as follows:

1. Specific unit/dwelling is owned, rented, or occupied under legally enforceable agreement
2. Same responsibilities/protections from eviction as all tenants under landlord tenant law of state, county, city, or other designated entity
3. If tenant laws do not apply, state ensures lease, residency agreement, or other written agreement is in place providing protections to address eviction processes and appeals comparable to those provided under the jurisdiction's landlord tenant law
4. Each individual has privacy in their sleeping or living unit
5. Units have lockable entrance doors, with the individual and appropriate staff having keys to doors as needed
6. Individuals sharing units have a choice of roommates
7. Individuals have the freedom to furnish and decorate their sleeping or living units within the lease or other agreement
8. Individuals have freedom and support to control their schedules and activities and have access to food any time
9. Individuals may have visitors at any time
10. Setting is physically accessible to the individual

There were also questions reflecting the criteria that the settings optimize individual initiative, autonomy, and independence in making life choices.

Table 6 contains the results from these questions.

Table 6. Right of Privacy, Choice, and Independence in Residential Setting

Question	Yes			
	Residential Participants		Providers	
	Percentage (Frequency)	N	Percentage (Frequency)	N
Entrance doors to unit lock	88.0% (228)	259	80.5% (91)	113
Only the necessary staff have keys to the unit's entrance door	89.6% (199)	222	85.3% (87)	102
Participants are able to lock bedroom door	61.5% (134)	218	81.6% (84)	103
Participants are able to lock bathroom door	70.6% (178)	252	85.8% (97)	113
Participants have access to a phone, computer, or other like items to have private conversations at any time	79.2% (198)	250	98.2% (111)	113
Participants were given the choice of a private unit	45.3% (115)	254	79.6% (90)	113
Participants with roommates were able to choose their roommate	40.9% (65)	159	81.0% (64)	79
Participants given a lease or other similar document describing their rights in the event of an eviction	38.2% (89)	233	69.2% (74)	107

Question	Yes			
	Residential Participants		Providers	
	Percentage (Frequency)	N	Percentage (Frequency)	N
Participants have access to food at any time	71.9% (182)	253	64.2% (70)	109
Participants are allowed to eat anywhere they want	58.0% (145)	250	66.4% (73)	110
Participants are able choose their clothing each day	86.9% (218)	251	96.4% (106)	110
Participants are able to choose how to groom themselves each day	83.8% (207)	247	85.5% (94)	110
Participants are able to decorate their own space as they wish	92.8% (232)	250	96.4% (106)	110
Participants are able to come and go from the unit at any time	55.3% (136)	246	72.6% (77)	106
Participants are allowed to have visitors at any time	93.8% (180)	192	85.7% (90)	105
Private space is available to meet with visitors	91.2% (198)	217	96.2% (102)	106
There are barriers present that prevent participants from getting to all areas in the unit	20.0% (50)	250	30.8% (32)	104

There are several questions to which a similar percentage of participants and providers responded in the affirmative (within 8 percentage points), including entrance doors locking, only the necessary staff having keys, participants having access to food at any time and being able to eat anywhere they want, participants being able to groom themselves and choose their own clothing every day, participants being able to decorate their own space, participants being allowed to have visitors at any time, and participants having a private space to meet their visitors. Of note within these criteria are that 80.5 percent of providers indicated that the entrance doors

lock; of those, 85.3 percent indicated that only the necessary staff have keys. In terms of access to food, participants and providers are close in their pattern of responses; 71.9 percent of participants note that they have access to food at any time, and 64.2 percent of providers indicate participants have access to food at any time. Looking at individual autonomy, the question regarding the participants' ability to choose how to groom themselves each day resulted in 83.8 percent of participants responding "yes" and 85.5 percent of providers responding "yes." Finally, 85.7 percent of providers indicated that participants are allowed to have visitors at any time, while 93.8 percent of participants replied they are allowed to have visitors at any time.

Many of the remaining questions illustrated a bigger difference between participants and providers. For instance, the questions regarding the ability to lock one's bedroom door and the bathroom door are indicators about whether the individuals have privacy in their sleeping or living units. Of providers, 81.6 percent indicated participants are able to lock the bedroom door, while only 61.5 percent of participants indicated they are able to do so. Being able to lock the bathroom door also elicited a difference between providers (85.8 percent) and participants (70.6 percent). Finally, the ability of participants to use a phone, computer, or other like item to have private conversations at any time indicates privacy as well as autonomy, and there were again differences between providers (98.2 percent) and participants (72.2 percent).

Additional areas that appear to be of concern with respect to the criteria are participants being given a choice of a private unit (participants: 45.3 percent, providers: 79.6 percent); participants being able to choose their roommate (participants: 40.9 percent, providers: 81.0 percent); and participants being able to come and go as they wish, which indicates independence in making life choices and controlling one's own schedule (participants: 55.3 percent, providers: 72.6 percent). Finally, 69.2 percent of providers indicated that participants were given a lease or other similar document, while only 38.2 percent of participants noted signing such a document. It is possible the participant percentage is lower because they were asked if they signed a lease versus being given a lease (as the providers were asked).

A final question about privacy touched on the use of cameras. When asked, 12.4 percent of providers responded that cameras are used in the unit to monitor residents. Participants were not asked a similar question. To protect privacy, it is important to understand when and why cameras are used, as well as the policies in place surrounding their use.

It is important to note that several of the criteria that are at 85 percent in the affirmative (yes) or below are criteria that can be modified if necessary based on individual need. Any changes to privacy items (for example, doors that lock), access to food, and the freedom to control one's own schedule or have visitors at any time would need to be documented in the participant's person-centered plan with the justification as to why a modification is necessary.

Participant and Case Manager Brief Comparison

Participants and case managers were both asked several of the same questions about the person-centered planning process and participants' service preferences. While person-centered planning is already supposed to be in effect, it is important to gain an understanding of any similarities or differences between these two groups, as the state is interested in developing technical assistance tools and procedures for on-going monitoring. Of note, the Final Rule criteria state that "settings are selected by the individual from among options, including non-disability specific settings and an option for a private unit in a residential setting; further, person-centered service plans document the options based on the individual's needs, preferences, and for residential settings, the individual's resources."

Table 7 illustrates the results from the questions asked about participants' services preferences.

Table 7. Participant Service Preferences Compared

Participant Service Preferences	Participant		Case Manager	
	Percentage (Frequency)	N	Percentage (Frequency)	N
	Participants informed of services eligible to receive	65.3% (409)	626	94.3% (150)
Participants informed of options for service providers	69.1% (432)	625	94.3% (148)	157
Participants choosing service providers		624		157
Participants choose all of their service providers	58.8% (367)		77.7% (122)	
Participants choose some of their service providers	25.0% (156)		20.4% (32)	
Participants did not choose any of their service providers	16.2% (101)		1.9% (3)	
Participants know how to request a new service provider	61.1% (384)	628	85.2% (127)	149

When participants meet with their case managers to develop their person-centered plan, they are supposed to be informed of all of the services they are eligible for and the provider options for those services. Of case managers, 94.3 percent responded that participants are informed of all of the services for which they are eligible, while 65.3 of participants reported getting this information. The pattern is similar regarding information about service provider options: 94.3 percent of case managers replied participants are informed of their provider options, while 69.1 percent of participants reported being informed.

Additionally, participants should be choosing their service providers and should be informed of the process to request a new service provider. Of case managers, 77.7 percent indicated that participants choose all of their service providers, while 58.8 percent of participants indicated they choose all of their service providers. With respect to knowing how to request a new service provider, 85.2 percent of case managers reported participants know how to do this, while 61.1 percent of participants indicated they knew how.

Summary of Comment Sections

As noted earlier, there were 152 comments from participants, 32 from providers, and 43 from case managers. Comments of “none” and “no comments at this time” were excluded from the final analysis. The comments were categorized into the following categories: HCBS Final Rule requirements (66 comments), services and service delivery (28 comments), satisfaction with provider (11 positive and 4 negative comments) requests for assistance (12 comments), general (33 comments), and survey instrument (65 comments). There were times the comments were categorized into multiple categories.

Table 8 provides examples of each type of comment category, with comments presented as they were written.

Table 8. Examples of Comments by Type of Respondent and Category

Category	Type of Respondent	Comment
HCBS Final Rule	Participant	Individual with severe autism with long history of elopement and SIBs (self-injurious behaviors). It would be unsafe to lock bedroom doors, use the stove, or to leave the residence without staff. Also required to wear shoes and coat in winter for health and safety.
	Provider	We try to make our facility as home like as possible and give residents as much independence as possible without comprising their health or safety of themselves or others.

Category	Type of Respondent	Comment
Services and service delivery	Case Manager	Some of these questions do not address the communication barriers that I face with deaf individuals. The language that the plan is written in might not be understood by the individual. The deaf individual does not have a lot of options for which agency provides services for them that meet their communication needs.
	Participant	Some family caregivers spend more than 40 hours a week providing care to loved ones, which is the equivalent of a full time job. Other family caregivers may spend 20-39 hours assisting loved ones in need of care. New Directions waiver allows the recipient a special program which allows them to self-direct their funds and compensate the natural support, or anyone else, to provide the in-home care. THIS ASPECT OF THE WAIVER SHOULD REMAIN IN EFFECT FOR THE STATE OF MD.
Satisfaction with provider: Positive	Participant	The quality of life and level of help is very dependent on excellent staff from the agency provider. I am lucky that at this moment in time I have good staff support who really cares about the clients. It may not always be that way.
Satisfaction with provider: Negative	Participant	Just because I'm mentally alert at 96, they treat me like I don't need assistance in doing things. Everything seems like it's a big chore for them to do.

Category	Type of Respondent	Comment
Requests for assistance	Participant	I as caregiver have an EXTREMELY difficult time with the requalification process that must be done EVERY YEAR. My participant is not suddenly going to regain her sight, become 20 years younger, be able to return to work, and after a point having to repeat this process is demeaning. My participant has no living family so if something happens to me no one is willing to take this process over for her. AND Social Security refuses to acknowledge my Power of Attorney and it is VERY difficult to get the necessary information from them. The social worker who is supposed to help me with certain tasks REFUSES to help.
	Participant	Want to relocate to my family home's vicinity; yet, no one will assist me.
Survey instrument comments	Participant	Some questions do not take into account person's abilities or cognitive level.
	Provider	It was difficult to definitively state yes or no to some questions as we serve a wide range of individuals from total care/profound ID to independent, including four apartments for the elderly and medically fragile that are staffed with CNAs.
General comments	Provider	All of our Individuals have one on one support.
	Case Manager	Plan Participant is mildly mentally challenged and sometimes becomes frustrated with so much data collection and very slow action on that information.

Limitations

A limitation of the participant and provider surveys was that they grouped multiple waiver populations together. While the questions were based on the HCBS settings Final Rule criteria, with which all waivers must comply, the questions did not account for the diverse waiver populations that are

served in the state of Maryland. Any further assessments may need to be done for specific waiver groups. Additionally, it may also be necessary to investigate how to account for differences in functional levels and abilities when surveying participants in order to achieve a true picture of their service experiences.

The majority of the answer choices were limited to yes/no in order to get rough estimates of potential trouble areas. Future assessments should allow respondents more flexibility in their answer choices, particularly to account for providers who have multiple sites that may be run differently. Alternatively, future assessments could require that providers assess each site.

Missing data was an issue across all three surveys, which is most likely a reflection of the items noted above. In addition, while there were multiple drafts of the surveys completed to reduce the number of questions, they were still long, which may have led to people skipping questions; routinely the lowest percentage of missing data occurred on the first question and the highest on the last question.

Given these limitations, the surveys still accomplished their intent, which was to begin the process of determining what HCBS residential settings look like in the Maryland. For example, there are providers who noted their settings are institutional—this is not allowed under the Final Rule. Additionally, participants' choice of living arrangements and access to food are also areas that need further assessment.

Discussion and Next Steps

Next steps should include prioritizing the following areas; those settings that may be in institutions, settings that may be isolating to participants (multiple provider settings close to each other and settings that serve only those with disabilities), and settings with criteria that had lower affirmative response rates (such as access to food, locking the front door, and lease issues). The methods for further assessment also need to be determined. For instance, 12 (10.5 percent of) providers indicated they served people in settings that are not allowed under HCBS (a setting in a publicly or privately owned facility that provides inpatient institutional treatment). These settings should be a top priority for additional assessment—potentially via a site visit—to determine if this is truly the case.

There were also provider settings that met some of the criteria for settings presumed not to be home and community based. These may also need further assessment to determine what is occurring in the field. Of providers, 30.6 percent indicated their settings were near other settings run by the provider for people with disabilities. If used as an estimate for settings potentially subject to heightened scrutiny, roughly 169 residential providers would need to be further evaluated. Additional criteria regarding heightened scrutiny includes settings designed specifically for people with disabilities and that serve primarily individuals with disabilities. A majority of providers responded in the affirmative to these questions, which could simply mean additional information may need to be gathered demonstrating how participants are integrated into the community.

An individual's control of their personal resources is another area that needs further study, as 29.2 percent of providers indicated all individuals residing in their settings had to have a representative payee, which seems contradictory to the Final Rule criteria. Additionally, only 25.5 percent of participants indicated they are in charge of their own banking.

When it comes to community access and involvement, transportation appears to be an issue, with 72.2 percent of providers indicating public transportation is accessible from their setting and only 48.2 percent of participants indicating they have access to public transportation.

In terms of privacy and autonomy, there seems to be discord between participants and providers regarding filing complaints. While 86.0 percent of providers report that information about filing a complaint is posted in an easy-to-find location, 54.0 percent of participants responded in the same manner. Additionally, 62.9 percent of participants indicated they could make a complaint without providing their name, while 94.8 percent of providers responded this was possible. This could simply be a matter of clarifying policy.

Additional areas of concern in residential settings are signing a lease, choice of private room, choice of roommate, privacy, food, and barriers placed. The majority (69.2 percent) of providers indicated participants were given a lease, while 38.2 percent of participants indicated they signed a lease. There were also differences regarding participants being informed about a choice of a private room (participants: 45.3 percent; providers: 79.6 percent) and participants choosing their roommate (participants: 40.9 percent; providers: 81.0 percent). With respect to privacy, a few providers (12.4 percent) indicated that cameras were used to monitor residents. The Final Rule does not forbid this practice, but when and why camera use occurs and the policies surrounding it may need to be addressed. While locking the entrance door is a specific item in the Final Rule that 80.5 percent of providers indicated was occurring, there were significant differences between providers and participants regarding locking bedroom and bathroom doors. The Final Rule does not state bathroom and bedroom doors need to lock, but providers do need to ensure privacy, whether that be participants being able to lock those doors or the assurance of people knocking and asking for permission to enter. With respect to access to food, 64.2 percent of providers indicated food was accessible at any time. Finally, 30.8 percent of providers indicated barriers are present that prevent participants from getting to all areas of the unit.

The reason for non-adherence in some areas may be due to the participants' level of functioning and the need for safety. Providers made the following observations:

“There are some exceptions based on individuals' special needs, for example a basement door may be kept locked if the staircase represents a risk of falls to the residents and the basement is not used as living space, and some individuals may have limited access to use of the kitchen due to safety concerns. Residential agreements do not include information specific to eviction rights because providers are not permitted to discharge a resident in the absence of advance approval from DDA.”

“For some areas, limitations are imposed due to the individuals' inability to safely negotiate their environment or use appliances such as stoves and ovens, or individually manage bank accounts. Most of the individuals in this program are diagnosed with severe to profound intellectually disability and require total care.”

“We may place a gate or a chain across stairs to keep a wheelchair from falling down the steps. It's a barrier for safety, not to restrict an individual's rights. Individuals we serve have ID/DD and may not safely be able to come and go, or have visitors whenever they choose. Again, this is a safety issue that may vary from person to person.”

What is especially important in the last comment is that policies may vary from person to person. As further assessments are conducted, it is important to remember that the Final Rule allows for modifications on an individual basis. That said, blanket policies regarding limited access to food or no locks on entrance doors would be contradictory to the Final Rule.

It is also important to remember that the intent of the Final Rule is to ensure participants are integrated into the community. In addition, participants' wants and needs should be paramount in this process. One participant expressed the following:

I prefer to be in a group home with housemates who do not hurt me, with many people to interact with (or a dormitory with my own room), but I feel that regulations are forcing me into an apartment alone, with nobody nearby to talk to. Don't take away my preference of a house with three to six people like me, with church and neighbors around nearby.

In the efforts to ensure integration, it is important to make sure participants are integrated in ways that are comfortable to them.

Moving forward, potential next steps could include in-depth provider assessments that are specific to the different waivers, as well as the development of tool to conduct site visits. Depending on the participant waiver group, focus groups may prove to be a better method to illicit feedback in the future. Educational materials regarding provider expectations may also need to be developed. Finally, a process of oversight will need to be created to ensure that when compliance with the Final Rule is achieved, it continues.

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Appendix A. Case Manager Survey Results

As noted at the beginning of this report, the case manager survey was conducted to help determine what is currently happening in the field with respect to the process of person-centered planning and person-centered plans. Of the 187 respondents, 61.7 percent served participants in the Community Pathways Waiver, 25.3 percent served participants in the Autism Waiver, 11.1 percent served individuals in the HCBOW, and 1.9 percent served individuals in the Traumatic Brain Injury Waiver. One of the requirements of person-centered planning is that it be conflict-free, meaning service providers should not be writing the service plans for individuals to whom they are providing services. Rather, a separate entity (the case manager, resource coordinator, supports planner, etc.) should be writing the plan. The following criteria have also been codified by the Final Rule with respect to person-centered planning:

1. Driven by the individual
2. Includes people chosen by the individual
3. Provides the necessary information and support to ensure that the individual directs the process to the maximum extent possible
4. Is timely and occurs at times/locations of convenience to the individual
5. Reflects cultural considerations and uses plain language
6. Includes strategies for solving disagreement
7. Offers choices to the individual regarding services and supports the individual receives and from whom
8. Provides a method to request updates
9. Reflects what is important to the individual to ensure delivery of services in a manner reflecting personal preferences and ensuring health and welfare
10. Identifies the strengths, preferences, needs (clinical and support), and desired outcomes of the individual
11. Includes whether and what services are self-directed
12. Includes individually identified goals and preferences related to relationships, community participation, employment, income and savings, healthcare and wellness, education, and others
13. Includes risk factors and plans to minimize them
14. Includes backup plans and strategies when needed
15. Includes individuals important in supporting the individual
16. Includes individuals responsible for monitoring the plan

- 17. Is distributed to the individual and others involved in the plan
- 18. Includes purchase and control of self-directed services
- 19. Excludes unnecessary or inappropriate services and supports

Table 9 summarizes the results of the case manager survey.

Table 9. Case Managers: Person-Centered Planning

Question	Yes	
	Percentage (Frequency)	N
Individuals choose who participates in writing their service plans		144
Individuals pick all the participants	39.6% (57)	
Individuals pick some of the participants	43.8% (63)	
Individuals do not pick any of the participants	16.7% (24)	
Individuals pick the time of day for their service plan meetings	81.8% (121)	148
Individuals pick the location of their service plan meetings	76.2% (112)	147
Individuals are given the opportunity to ask questions when writing their service plan	96.5% (139)	144
Individuals' needs are correctly identified in the service plan	97.2% (140)	144
Individuals' choice of goals in their service plans		144

Question	Yes	
Individuals choose all of their goals	52.1% (75)	
Individuals choose some of their goals	45.8% (66)	
Individuals do not choose any of their goals	2.1% (3)	
Individuals' strengths are identified in their service plans	90.3% (130)	144
Items are identified in the service plan to lower any risks identified in their risk assessment		145
Yes	62.1% (90)	
No	4.1% (6)	
Does not apply. Risk assessments are not completed.	33.8% (49)	
Service plans are written in plain language that the individual understands	90.3% (130)	144
Individuals' service plans include how paid providers will assist them in reaching their goals	86.6% (123)	142
Individuals' service plans include how unpaid providers will assist them in reaching their goals	67.8% (97)	143
Individuals are able to request a time to update their service plans, outside of annual reviews	92.9% (131)	141
The person responsible for monitoring the service plan is documented in the plan	97.2% (137)	141
Individuals are told how to make a complaint if they do not agree with their plan	77.8% (112)	144

Question	Yes	
Individuals are given a copy of their service plan	94.4% (136)	144
Service providers sign the service plans for individuals to whom they provide services	86.3% (120)	139

There are several areas for which a high percentage of case managers reported in the affirmative, including individuals are given the opportunity to ask questions when writing their service plan (96.5 percent); individuals' needs are correctly identified in the plan (97.2 percent); individuals' strengths are identified in their service plans (90.3 percent); service plans are written in plain language that the individual understands (90.3 percent); individuals are able to request a time to update their service plans outside of annual reviews (92.9 percent); the person responsible for monitoring the service plan is documented in the plan (97.2 percent); and individuals are given a copy of their service plan (94.4 percent). While it is promising that the percentages are high, there is a concern that the percentages are a reflection of policy and not what is going in reality. For instance, one case manager provided the following comment:

I would say our policy is to require many of these processes, but I believe reality falls very short, especially given the number of new resource coordinators across the system. I also believe the element of provider education severely limits the coordinator's efforts, even if the intent is to follow the policy. In the end, service providers do not believe the service plan must come from the coordinator, nor do they agree to services that they don't agree to (said on purpose to make a point). We still have providers mandating what the plan will include. There is a critical need to help providers understand their role, as well as the role of the coordinator, in planning, or we will never move closer to person-centered/directed planning.

It is apparent from this case manager's comment that the intent and desire is present to do the best job possible on behalf of the client, but assistance is needed in educating all parts of the system regarding what person-centered planning involves, including it being conflict-free. Another comment from a case manager stated, "As a service coordinator I could not speak to most of these questions because I do not participate in treatment plan meetings, or write the plans themselves." This again points to the need for education regarding person-centered planning across the system.

There were also several areas where the affirmative responses are low. For instance, 62.1 percent of case managers reported that items from the risk assessment are identified in the service plan. In addition, 33.8 percent of case managers reported that risk assessments are not completed. This is especially cause for concern when the completion of risk assessment is included in the waiver application. Other areas of low response included documenting how unpaid providers would assist participants in reaching their goals (67.8 percent) and participants being told how to make a complaint if they do not agree with their plan (77.8 percent).