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DISABILITIES

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A GUIDE TO THE HOME- AND COMMUNITY-BASED SERVICES (HCBS) FINAL SETTINGS RULE

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Part I

Background

A Guide to the Home- and Community-Based Services (HCBS) Final Settings Rule



There are approximately 4.6 million individuals in the United States who receive Medicaid Home and Community-Based Services (HCBS) with a combined Fiscal Year (FY) 2017 state and federal funding of \$82.7 billion (Musumeci, Chidambaram, & Watts, 2019). Musumeci et al. also reported that in FY 2017, there were 8,800 Utah individuals on a Medicaid 1915 (c) HCBS

waiver; people with intellectual disabilities represented 59% (5,200) of these waiver recipients. HCBS waivers were conceptualized as a way to provide a pathway to community integration for individuals with disabilities who traditionally received services in restrictive, institutional settings. While HCBS waivers have existed since 1981, the intent of these waivers has not been fully achieved. That is, some HCBS waiver recipients continue to have little choice in the supports and services they receive and do not have meaningful access to integration in community settings and activities.

Advocacy groups, researchers, and policy makers recognized this disparity and worked to improve meaningful integrated outcomes for people with disabilities for years. The 2014 HCBS Final Settings Rule represents a culmination of advocacy, legislation, and policy making efforts. It is important to note that the Final Settings Rule is a progression and continuation of the values and ideas distilled in early legislation. Therefore, HCBS providers, parents, and others who are involved in supporting people with disabilities should have a basic understanding of key pieces of legislation. This legislation not only influenced the Final Settings Rule but is used to fund services and supports for meaningful community integration. The first section of this manual will provide a brief review of key legislation that served as a catalysis for change in the way people with disabilities access the community and receive supports. This legislation includes the Rehabilitation Act, as Amended (1973), Public law 94-142, the Education of All Handicapped Children Act, as amended (1975), The Social Security Act, as amended (1935), and the Americans with Disabilities Act, as amended (1990). The second section of this manual will provide a review of key provisions of the Centers for Medicare & Medicaid Services (CMS) HCBS Final Settings Rule.

People with disabilities represent one of the largest minority groups in the United States. In fact, according to the 2017 American Community Survey, there are roughly 40,714,800

noninstitutionalized people with a disability in the United States (Erickson, Lee, & von Schrader, 2017). Unfortunately, many people with disabilities have and continue to be marginalized and have not been afforded the same opportunities as people without disabilities in terms of access, community services, and education. Over the past 50 years, advocacy efforts by people with disabilities and their families have resulted in improved civil rights and social support programs for people with disabilities.

The Rehabilitation Act of 1973

The Rehabilitation Act was the first major piece of civil rights legislation that protected qualified individuals with disabilities from discrimination in any program or activity that received federal funding. This Act also expanded the scope of rehabilitation from merely physical disabilities to include people with significant intellectual and developmental disabilities. The Rehabilitation Act is designed to *empower individuals with disabilities to maximize employment, economic self-sufficiency, independence, and inclusion and integration into society, through – Statewide workforce investment systems; Independent living centers and services; research; training; demonstration projects; and the guarantee of equal opportunity; and To ensure that the Federal Government plays a leadership role in promoting the employment of individuals with disabilities, especially individuals with significant disabilities, and in assisting States and providers of services in fulfilling the aspirations of such individuals with disabilities for meaningful and gainful employment and independent living* (29 U.S.C § 701 (b)(1)). Figure 1 provides a brief summary of the intent and scope of the Rehabilitation Act.

Section 504 of the Rehabilitation Act

“No otherwise qualified individual with a disability...shall solely by reason of his or her disability, be excluded from participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving federal financial assistance.”

There are a number of provisions in the act that HCBS providers, parents, and others should understand as these provisions reinforce the value of meaningful community integration through employment. First, the 2014 amendments include the first Federal definition of **competitive integrated employment** (CIE). Understanding the definition of CIE is important for HCBS providers because it is referred to in the Final Settings Rule. According, the 2014 Rehabilitation Act amendments, CIE means:

...work that is performed on a full-time or part-time basis (including self-employment)—for which an individual (a) Earns at least minimum wage, (b) Is paid commensurate wages and benefits, (c) Is in a location where the employee interacts with other persons without disabilities, and (d) is presented with opportunities for advancement.

The Rehabilitation Act of 1973, as Amended

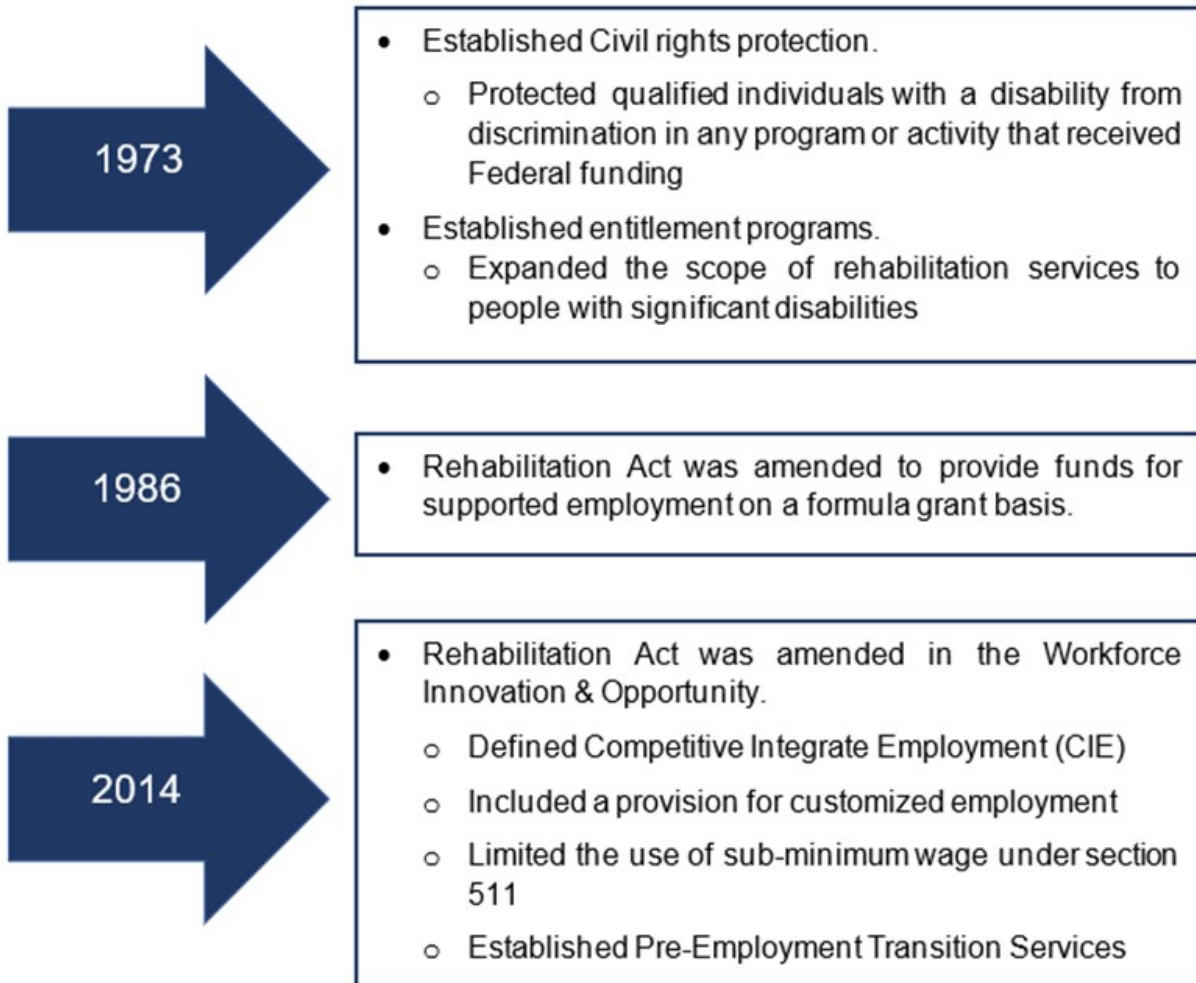


Figure 1. Brief Summary of the Rehabilitation Act of 1973 as amended.

Another important provision of the Rehabilitation Act is related to supported and customized employment. Supported employment was included as a service provision in the 1986 amendments, and the 2014 amendments added a definition of customized employment as part of this provision

The 2014 amendments also included a provision for Pre-Employment Transition Services (Pre-ETS). For this provision, state rehabilitation agencies must use 15% of their Title on funding to provide a number of services to students with disabilities. These include, job exploration counseling, work-based learning, counseling, workplace readiness training, and instruction in self-advocacy. A final important provision of the 2014 Rehabilitation Act

Amendments is Section 511, which limits the use of subminimum wages. Section 511 places clear limitation on paying youth with disabilities (ages 14-24 years-old) subminimum wages. Before a youth with a disability can be paid a rate below minimum wage, the youth must (a) receive pre-employment transition services, (b) be referred to VR for services, and (c) receive career counseling. There must be proof that each of the requirements listed above are met. First, the youth received pre-employment transition services, the individual applied for VR and was found ineligible, or the individual was found eligible for VR services and has been working on an employment goal for a reasonable period of time without success.

Supported Employment

Supported employment means competitive integrated employment, including customized employment, or employment in an integrated work setting in which an individual with a most significant disability, including a youth with a most significant disability, is working on a short-term basis toward competitive integrated employment, that is individualized and customized, consistent with the unique strengths, abilities, interests, and informed choice of the individual, including with ongoing support services for individuals with the most significant disabilities

The Education for All Handicapped Children Act

Public Law 94-142, The Education for all Handicapped Children Act (EAHCA), was enacted in 1975 to provide students with disabilities the opportunity to receive a public education. Since its inception, Part B of the EAHCA made free and appropriate public education (FAPE) available to students with disabilities who were previously excluded from public school. The act guaranteed several basic rights to eligible students with disabilities including: (1) a free, appropriate public education (FAPE), (2) an education in the least restrictive environment (LRE), and (3) an individualized education program (IEP; Huefner, 2006). Unfortunately, while students with disabilities were provided access to special education and related services, many struggled to adjust to the demands of adult living after exiting school. In 1990 the act was amended and renamed the Individuals with Disabilities Education Act (IDEA). The 1990 amendments explicitly addressed school district responsibilities for helping students transition from school to adult life. The statute required that a student with disabilities' IEP to contain a statement of transition services. Congress stipulated that a statement of transition services should be prepared no later than age 16 and, when deemed appropriate, the statement should be prepared at age 14 or younger.

Another important aspect of IDEA is the “least restrictive environment” mandate. Prior to the mid-1970s, persons with disabilities in the United States were largely excluded from schooling, and were housed in residential institutional settings. Even when special education began in the mid-1970s most students with disabilities were educated in segregated classrooms or buildings that provided them with no opportunity to interact with their typically developing peers. Prior to 1997, the IDEA required each student’s IEP to provide a statement about the extent to which he or she would participate in the general education classroom—indicating a clear, if unspoken, presumption that students with disabilities would primarily be educated outside of the general education classroom, most likely in a segregated or self-contained setting. Inclusion advocates were successful in reversing this presumption in the 1997 reauthorization of IDEA. In 1997, the language in IDEA was literally reversed and required students’ IEPs to provide a statement justifying any time the student may spend outside of the general education classroom. Prior to 1997 only 20% of students with disabilities spent any time with their typically developing peers, but today over 90% of students with disabilities have the opportunity to participate in the general education classroom and curriculum with their peers. This movement for greater educational inclusion laid the groundwork for the increased emphasis on community integration on the Final Settings Rule.

Public Law 94-142 was and still is important legislation as it reinforces the idea that students with disabilities should be meaningfully included in all aspects of education. Moreover, the provision for transition services outlined in IDEA recognizes that meaningful inclusive education and employment experiences are directly linked to quality adult outcomes. Furthermore, “least restrictive environment” expectation in IDEA recognizes that students with disabilities have a right to be educated with their peers, and taken together with the transition planning provisions, it informs the provisions of the HCBS Settings rule that require greater inclusion in the community and employment settings. Providing timely and effective transition services is one way to prepare students with disabilities for integrated employment, inclusive social and recreational activities, and independent living, all of which are priorities of the Final Settings Rule.

The Social Security Act

Section 1915(c) of the Social Security Act of 1935, as amended authorizes the Medicaid HCBS waiver program. Section 1915(c) was created as part of the 1981 amendments to the Social Security Act. Prior to this amendment, the Medicaid program, which was created in 1965, provided little in the way of coverage for long-term services and supports



in the community but offered full coverage for institutional care. This discrepancy was often referred to as the Medicaid “*institutional bias*.”

HCBS waivers were specifically created to address this institutional bias so that Medicaid programs could provide coverage for services in homes and communities. Medicaid waivers are intended to complement the regular services that are available through the Medicaid state plan. A Medicaid waiver waives certain statutory requirements, like requiring services to be provided in an institutional setting, so a state can offer Medicaid beneficiaries the option of receiving services in their home and community. As outlined by the Center for Medicare and Medicaid Services (CMS) technical guide (2015), states have tremendous flexibility in designing waivers including:

1. Determining the target group(s) of Medicaid beneficiaries who are served through the waiver;
2. Specifying the services that are furnished to support waiver participants in the community;
3. Incorporating opportunities for participants to direct and manage their services;
4. Determining the qualifications of waiver providers;
5. Designing strategies to assure the health and welfare of waiver participants;
6. Managing a waiver to promote the cost-effective delivery of home- and community-based services;
7. Linking the delivery of waiver services to other state and local programs and their associated services delivery systems; and
8. Developing and implementing quality improvement strategies to ensure the waiver meets essential Federal statutory assurances and to continuously improve the effectiveness of the waiver in meeting participant needs.

This flexibility in the design and delivery of Medicaid home and community-based services allows a state to specifically design service options that are customized to the unique needs of people in the state. Utah has seven Medicaid 1915(c) waivers: Acquired Brain Injury Waiver, Aging Waiver (for individuals 65 and older), Community Supports Waiver, Medically Complex Children’s Waiver, New Choices Waiver, Physical Disabilities Waver,

and Waiver for Technology Dependent Children. Figure 2 provides information on three of the primary waivers for which Utah HCBS providers contract to provide services; Community Supports Waiver, Acquired Brain Injury Waiver, and New Choices Waiver.

Utah Home & Community-Based Services Waiver Programs	
<p>Community Supports Waiver</p> <p>This waiver is designed to provide services statewide to help persons with intellectual disabilities or persons with conditions related to intellectual disabilities remain in their homes or other community-based settings. Individuals are able to live as independently as possible with supportive services provided through this waiver program.</p>	<p>Services Available Through Community Supports Waiver Services</p> <p>Behavior Consolation, Chore Services, Companion Services, Day Supports, Homemaker Services, Residential Habilitation, Respite Supported Living, Personal Assistance, Supported Employment</p>
<p>Acquired Brain Injury Waiver</p> <p>This waiver is designed to provide services statewide to help people with an acquired brain injury to remain in their homes or other community-based settings. Individuals are able to live as independently as possible with supportive services provided through this waiver.</p>	<p>Services Available Through Acquired Brain Injury Waiver</p> <p>Behavior Consolation, Chore Services, Companion Services, Day Supports, Homemaker Services, Residential Habilitation, Respite Supported Living, Personal Assistance, Supported Employment, Cognitive Retraining</p>
<p>New Choices Waiver</p> <p>The New Choices Waiver program is designed to serve individuals who are residing long term in a nursing facility, licensed assisted living facility, licensed small health care (Type N) facility or another type of Utah licensed medical institution (except institutions for mental disease). The program offers an option for these individuals to move into integrated community-based settings if they wish to do so and if their needs can be safely met in the setting that they have chosen.</p>	<p>Services Available Through New Choices Waiver</p> <p>Adult Day Care, Adult Residential Services, Assistive Technology, Attendant Care, Caregiver Training, Case Management, Chore Services, Habilitation Services, Consumer Preparation Services,</p>

Figure 2. Utah Home- and Community-Based Services Waiver.

The Americans with Disabilities Act



The ADA was signed into law in 1990 and amended in 2008. This landmark legislation guarantees important civil rights for people with disabilities, and ensures that people with disabilities have equal opportunities for access and employment. The ADA extends the civil rights, non-discrimination mandate of Section 504 of the Rehabilitation Act to private employers and organizations that do not receive financial assistance. In the ADA's

findings, Congress stated that people with disabilities continue to face forms of discrimination and isolation based on their disability. "Historically, society has tended to isolate and segregate individuals with disabilities, and, despite some improvements, such forms of discrimination against individuals with disabilities continue to be a serious and pervasive social problem" (42 U.S.C § 12102 (a)(2)).

The broader protections outlined in the five titles of the ADA prohibit discrimination against people with disabilities in employment, public services, public accommodations, transportation, and telecommunications. Professionals, parents, and individuals with disabilities should also understand the Title II integration mandate. The mandate states: "a public entity shall administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities" (28 C.F.R. § 35.130(d)). The integration mandate influenced the way programs and services are provided to people with disabilities and it enables individuals with disabilities to interact with persons without disabilities to the fullest extent possible. Figure 3 provides information about how the U.S. Department of Justice (2011) defines an integrated setting and segregated settings under the ADA.

What is an Integrated and Segregated Setting?

Integrated Settings

- Integrated settings provide individuals with disabilities opportunities to live, work, and receive services in the greater community, like individuals without disabilities.
- Integrated settings are located in mainstream society.
- Integrated settings offer access to community activities and opportunities at times, frequencies and with persons of an individual's choosing.
- Integrating settings afford individuals choice in their daily living activities.
- Integrated settings provide individuals with disabilities the opportunity to interact with nondisabled peers to the fullest extent possible.

Segregated Settings

- Congregate settings populated exclusively or primarily with individuals with disabilities.
- Congregate settings characterized by regimentation in daily activities, lack of privacy or autonomy, policies limiting visitors, or limits on individual's abilities to engage freely in community activities and to manage their own activities of daily living.
- Settings that provide daytime activities primarily with other individuals with disabilities.

Figure 3. U.S. Department of Justice definition of integrated and segregated settings.

Definitions of Key Terms and Phrases

Table 1

Definitions of HCBS Final Settings Rule Key Terms and Phrases

Terms or Phrase	Definition
Age-Appropriate Activity	<p>“Age appropriate” means the activity corresponds with a person’s chronological age. Generally, the content and context of an activity are what make it age-appropriate.</p> <p><i>Examples:</i></p> <ul style="list-style-type: none"> • During a meal, individuals are treated age appropriately and are not required to wear a bib. • Adult individuals are not required to participate in activities designed for children.
Competitive Integrated Employment (CIE)	<p>The Rehabilitation Act as amended (2014) defines CIE as work that is performed on a full-time or part-time basis (including self-employment)—for which an individual (a) Earns at least minimum wage, (b) Is paid commensurate wages and benefits, (c) Is in a location where the employee interacts with other persons without disabilities, and (d) Is presented with opportunities for advancement.</p>
Center for Medicare and Medicaid Services (CMS)	<p>The CMS is the federal agency that works with states to administer Medicare and Medicaid. The CMS provides interpretive oversight and guidance regarding the Final Settings Rule.</p>
Home- and Community- Based Services	<p>The Medicaid Home and Community-Based services (HCBS) waiver program is authorized in Â§1915(c) of the Social Security Act. The program permits a state to furnish an array of home and community-based services that assist Medicaid beneficiaries to live in the community and avoid institutionalization. In Utah, there are seven HCBS waivers.</p>
Heightened Scrutiny Review	<p>A review designed to determine that settings do not have the qualities of an institution and that the settings do have the qualities of home and community-based settings.</p>
Integrated Setting	<p>The Department of Justice defined integrated settings as those that provide individuals with disabilities opportunities to live, work, and receive services in the greater community, like individuals without disabilities. Integrated settings offer individuals access to community activities and opportunities at times, frequencies and with persons of an individual’s choosing.</p>
Person-Centered	<p>CMS specifies that service planning for participants in Medicaid</p>

Terms or Phrase	Definition
Planning	<p>HCBS programs under section 1915(c) and 1915(i) of the Act must be developed through a person-centered planning process that addresses health and long-term services and support needs in a manner that reflects individual preferences and goals. The Final Settings Rule requires the person-centered planning process to be directed by the individual with long-term support needs and may include a representative whom the individual has freely chosen and others chosen by the individual to contribute to the process.</p>
Segregated Setting	<p>Segregated settings often have qualities of an institutional nature. Segregated settings include, but are not limited to: Congregate settings populated exclusively or primarily with people with disabilities.</p> <ul style="list-style-type: none"> • Congregate settings are characterized by regimentation in daily activities, lack of privacy or autonomy, policies limiting visitors, or limits on people’s ability to engage freely in community activities and to manage their own activities of daily living <p>Settings that provide for daytime activities primarily with other people with disabilities are also considered segregated.</p>
Settings that Isolate	<p>The setting is designed to provide people with disabilities multiple types of services and activities on-site, including housing, day services, medical, behavioral and therapeutic services, and/or social and recreational activities. People in the setting have limited, if any, interaction with the broader community. Settings that use/authorize interventions/restrictions that are used in institutional settings or are deemed unacceptable in Medicaid institutional settings (e.g. seclusion).</p> <p>Examples:</p> <ul style="list-style-type: none"> • <i>Gated/secured “community”</i> for people with disabilities: Gated communities typically consist primarily of people with disabilities and the staff that work with them. • <i>Residential schools</i>: These settings incorporate both the educational program and the residential program in the same building or in buildings in close proximity to each other (e.g. two buildings side by side). • <i>Multiple settings co-located and operationally related</i> (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, such that people’s ability

Terms or Phrase	Definition
	<p>to interact with the broader community is limited.</p> <p>See https://www.medicaid.gov/medicaid/hcbs/downloads/settings-that-isolate.pdf</p>
Settings Presumed Not to Be Home and Community-Based	Settings presumed not to be home and community based are (a) settings in a publicly or privately-owned facility providing inpatient treatment, (b) settings on grounds of, or adjacent to, a public institution, and (c) settings with the effect of isolating individuals from the broader community of individuals not receiving Medicaid HCBS.
Settings that are NOT Home and Community-Based	<p>Private and public institutions. A public institution is an inpatient facility that is financed and operated by a county, state, municipality, or other unit of government.</p> <p>Examples:</p> <ul style="list-style-type: none"> • Nursing facility • Institution for mental diseases (IMD) • Intermediate care facility for individuals with Intellectual disabilities (ICF/IID) • Hospital
Provider Owned/ Controlled Settings	A setting is provider-owned or controlled when the setting in which the individual resides is a specific physical place that is owned, co-owned, and/or operated by a provider of HCBS.



Part II:

The Home and Community-Based Waiver Services Final Settings Rule



The Center for Medicare and Medicaid Services (CMS) issued the Home and Community-Based Waiver Services (HCBS) Final Settings Rule (CMS2249-F/2296-F) in 2014. The Final Settings Rule was designed to enhance the quality of HCBS programs and increase opportunities for

individuals with disabilities to have meaningful access to integrated community settings. According to the CMS, the Final Settings Rule requirements establish an outcome-oriented definition that focus on both the nature and quality of an individual's experience. As such, the settings requirements are designed to maximize opportunities for individuals with disabilities to have access to the benefits of community living and the opportunity to receive services in the most integrated setting.

The Final Settings Rule allows states to develop a transformation process to meet these new requirements. One of the challenges of meeting these requirements, however, is ensuring that provisions set forth by the Final Settings Rule promote meaningful access to the integrated community (Friedman & Spassiani, 2017). That is, services and supports need to be designed to ensure that individuals with disabilities are not simply physically relocated to the community but rather access to community settings is individualized and supports a full range of meaningful options. Unfortunately, many individuals with disabilities and their families do not fully understand the complete impact of the Final Settings Rule and provider organizations are struggling to understand and implement required changes (Friedman, 2018). Given these challenges, it is increasingly important for people with disabilities, family members, and provider organizations to understand how to develop supports and services that meet the regulatory intent of the Final Settings Rule. This manual is designed to be used by providers who receive HCBS funding as a guide on how to meet the requirements of the Final Settings Rule. Part II of this manual provides specific information about HCBS terminology and provides a series of exploratory questions developed by the Center for Medicaid Services (CMS, n.d.) to assist with assessment of Final Settings Rule compliance for residential and non-residential settings. These questions should assist provider agencies with determining whether the residential and non-residential setting meet the Final Settings Rule requirements.

Quality Indicators

The Final Settings Rule promulgated specific regulatory changes designed to ensure the individuals receiving Medicaid funded HCBS are provided with opportunities to have meaningful community integration and choice. Specifically, as outlined in Section 441.301 (c)(4) any residential or non-residential setting where individuals live or receive HCBS

must have the five qualities outlined in Figure 4.

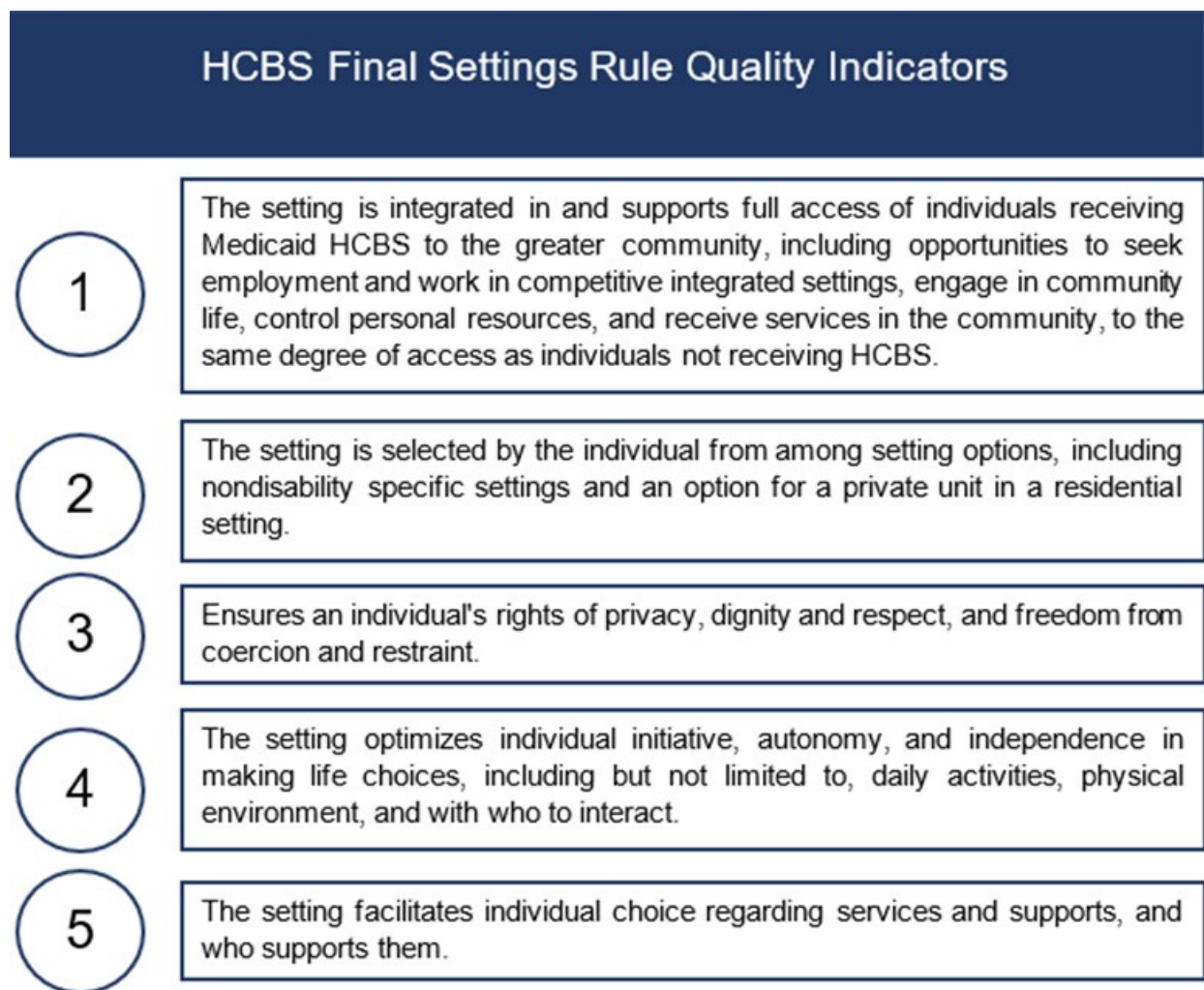


Figure 4. HCBS Final Settings Rule quality indicators.

HCBS Settings Characteristics

In addition to the quality indicators, the CMS outlines 12 settings characteristics that meet the Final Settings Rule criteria for both residential and non-residential HCBS settings. Some of the 12 characteristics apply to only residential settings while some apply to both residential and non-residential settings. Table 2 provides statutory language for each settings characteristic and its application to residential or non-residential settings. This manual will highlight how each of these characteristics align with specific provisions of the Final Settings Rule.

Table 2

HCBS Characteristics for Residential and Non-Residential Settings

HCBS Settings Characteristics	Residential	Non-Residential
1. 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.	X	X
2. The setting is selected by the individual from among setting options including nondisability specific settings and an option for a private unit in a residential setting. The setting options are identified and documented in the person-centered service plan and are based on the individual's needs, preferences, and, for residential settings, resources available for room and board.	X	X
3. The setting ensures an individual's rights of privacy, dignity, respect, and freedom from coercion and restraint.	X	X
4. The setting 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.	X	X
5. The setting facilitates individual choice regarding services and supports, and who provides them.	X	X
6. The individual has a lease or other legally enforceable agreement providing similar protections.	X	
7. The setting ensures the individual has privacy in their sleeping or living unit including lockable doors, choice of roommates, and freedom to furnish or decorate the unit.	X	
8. The setting ensures the individual has the freedom and support to control his/her own schedule and activities, and have access to food at any time.	X	
9. The individual can have visitors of his/her choosing at any time.	X	
10. The setting is physically accessible to the individual.	X	

HCBS Settings Characteristics	Residential	Non-Residential
11. The setting ensures that any modification of the HCBS Settings qualities and conditions is supported by a specific assessed need and justified in the person-centered service plan.	X	X
12. The setting enforces the Home and Community-Based Settings Regulation requirements.	X	X

HCBS Requirements for Person-Centered Planning

The HCBS Final Settings Rule reinforces the idea that person-centered planning is directly linked to positive community outcomes for HCBS recipients. Person-centered planning (PCP) should be a primary strategy that assists HCBS recipients with accessing



meaningful integrated settings and achieving valued outcomes such as competitive integrated employment. PCP emerged in the 1980's as a strategy to understand and discover how an individual with a disability would like to live his or her life and to determine what supports are needed to help the individual achieve his or her goals (O'Brien, O'Brien, & Mount, 1997). A number of requirements for the PCP process and

the person-centered service plan are outlined in the CMS, Home and Community-Based Services Waiver Requirements (42 CFR 441.301(c)(1), et seq.). Each of these requirements is discussed below. The HCBS requirements also stipulate that each PC service plan should be reviewed and revised upon reassessment of functional needs at least every 12 months or when the individual's circumstances or needs change significantly, or at the request of the individual.

Person-centered planning process. When facilitating the person-centered planning process, steps must be taken to ensure the individual with a disability leads the person-centered planning process, unless state law confers decision-making authority to a legal representative (42 CFR 441.301(c)(1)).

Some stories enhance life, others degrade it. So, we must be careful about the stories we tell, about the ways we define ourselves and other people. --*Burton Blatt*

Regardless of who has decision making authority, the person-centered

planning process should be driven by the individual receiving HCBS services to the maximum extent possible so that the HCBS recipient achieves person-centered outcomes in the most integrated setting.

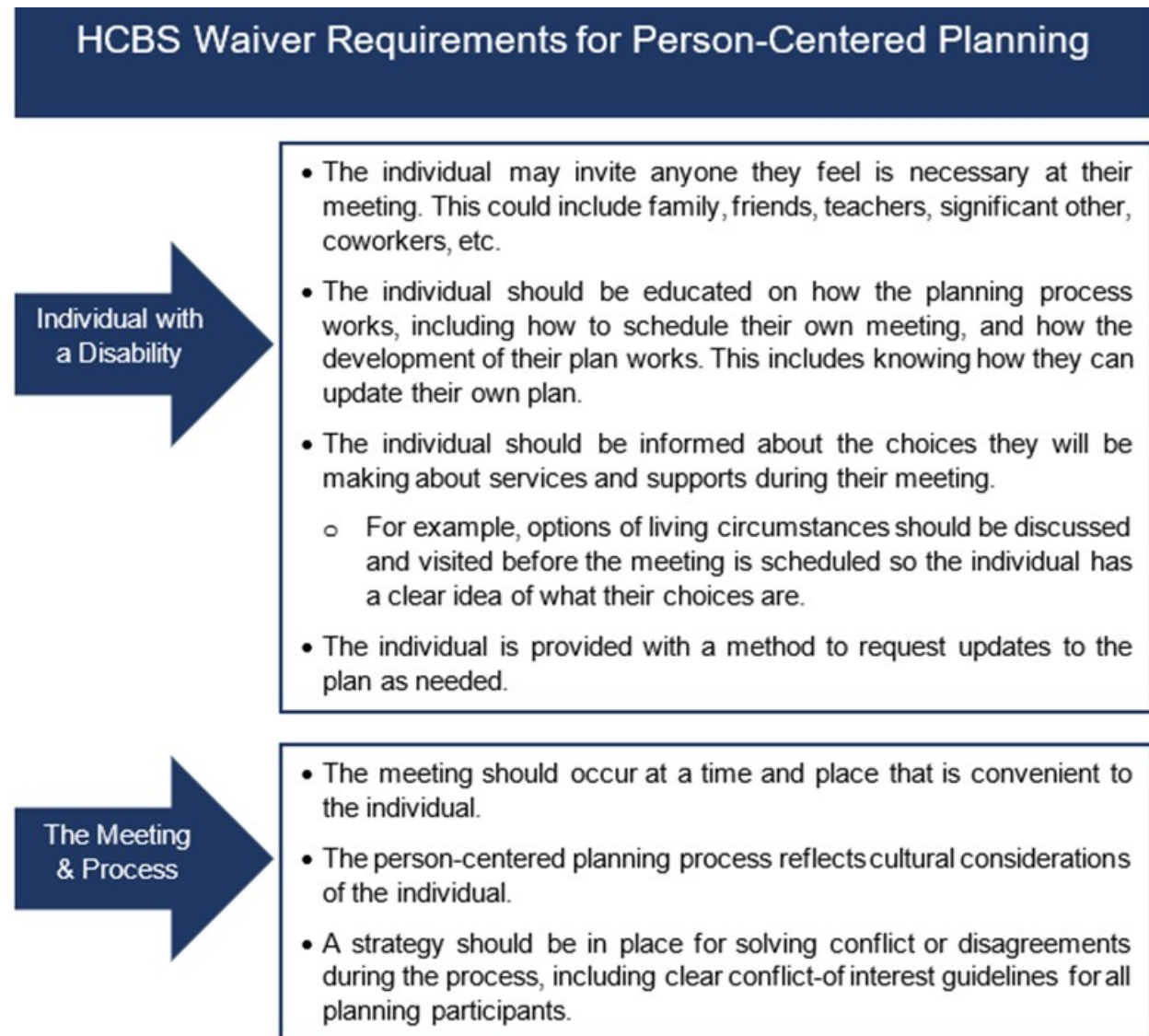


Figure 5. HCBS waiver requirements for person-centered planning.

The waiver requirements state that those who provide HCBS for the individual, or those who have an interest in or are employed by a provider of HCBS for the individual **must not provide case management or develop the person-centered service plan**, except when the State demonstrates the only willing and qualified entity to provide case management and/or develop person-centered plans in a geographic area also provides HCBS. The HCBS waiver requirements also stipulate that the person-centered process

should include a number of important elements (see Figure 5).

Person-centered service planning. The HCBS Waiver Requirements identifies 13 components which must be met within the written person-centered service plan (42 CFR 441.301(c)(2), et seq), Table 3 outlines each of these elements.

Table 3

HCBS Waiver Requirements for the Person-Centered Service Plan

Item	Requirement
1	The written plan must reflect that the setting in which the individual resides is chosen by the individual. The State must ensure that the setting chosen by the individual 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 written plan must reflect the individual's strengths and preferences.
3	The written plan must reflect clinical and support needs as identified through an assessment of functional need.
4	The written plan must include individually identified goals and desired outcome.
5	The written plan must reflect the services and supports (paid and unpaid) that will assist the individual to achieve identified goals, and the providers of those services and supports, including natural supports. Natural supports are unpaid supports that are provided voluntarily to the individual in lieu of 1915(c) HCBS waiver services and supports.
6	The written plan must reflect risk factors and measures in place to minimize them, including individualized back-up plans and strategies when needed.
7	The written plan must be understandable to the individual receiving services and supports, and the individuals important in supporting him or her. At a minimum, for the written plan to be understandable, it must be written in plain language and in a manner that is accessible to individuals with disabilities and persons who are limited English proficient.
8	The written plan must identify the individual and/or entity responsible for monitoring the plan.
9	The written plan must be finalized and agreed to, with the informed consent of the individual in writing, and signed by all individuals and providers responsible for its

Item	Requirement
	implementation.
10	The written plan must be distributed to the individual and other people involved in the plan.
11	The written plan must include those services, the purpose or control of which the individual elects to self-direct.
12	The written plan must prevent the provision of unnecessary or inappropriate services and supports.
13	The written plan must document that any modification of the additional conditions must be supported by a specific assessed need and justified in the person-centered service plan.



HCBS Requirements for Modifications

The HCBS Final Settings Rule allows for modifications of specific requirements for an HCBS recipient when individual modifications to settings qualities and conditions are supported by an assessed need and justified in the person-centered service plan. Specific modifications are not meant to eliminate choices or behaviors that support professionals feel are an inconvenience, but rather individualized modifications allow providers to serve individuals with the most complex needs in integrated settings to ensure the health, safety, and well-being of the HCBS recipient or others.

The CMS provides specific examples of modifications:

1. Providers in many states serve individuals with severe pica behavior (compulsive eating of non-food items), for whom the physical environment may need to be tightly controlled to prevent the occurrence of an individual behavior that can cause severe injury or death.
2. Some community providers support individuals with a history of sexual predation where line-of-sight supervision and limits on interaction with certain members of the community may need to be imposed.

3. Other community providers serve individuals with dementia for whom measures must be taken to account for safety needs in a person-centered manner, including concerns related to wandering.

Modifications, therefore, are made on an individual basis and must be supported by a specific, assessed need and modifications must be justified in the person-centered service plan. The Final Settings Rule outlines the following eight requirements that must be documented in the person-centered service plan before making any modification to individual settings or qualities. Figure 6 list each of these requirements.

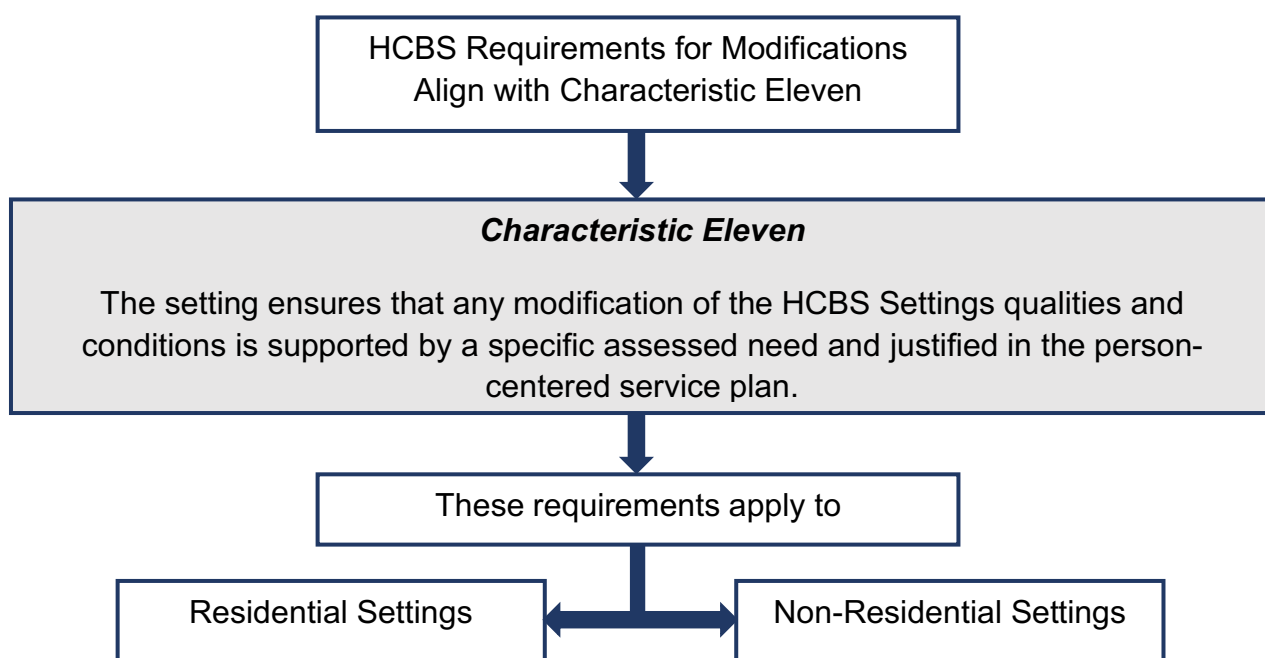


Figure 6. HCBS requirements for modifications.

Providers must ensure they are fully complying to the scope of the Final Settings Rule in regard to modifications. The CMS emphasizes that before any modification can be made, providers must document (a) that positive interventions were used prior to making a modification and (b) that less-intrusive methods did not successfully meet the individual's assessed needs. Providers must regularly collect data to measure the ongoing effectiveness of the modification and have established time limits for periodic reviews. Finally, the Final Settings Rule requires informed consent prior to making rights modifications. Informed consent requires the case manager for the individual to inform

the HCBS recipient of the assessed need of the proposed modification (see Figure 7).

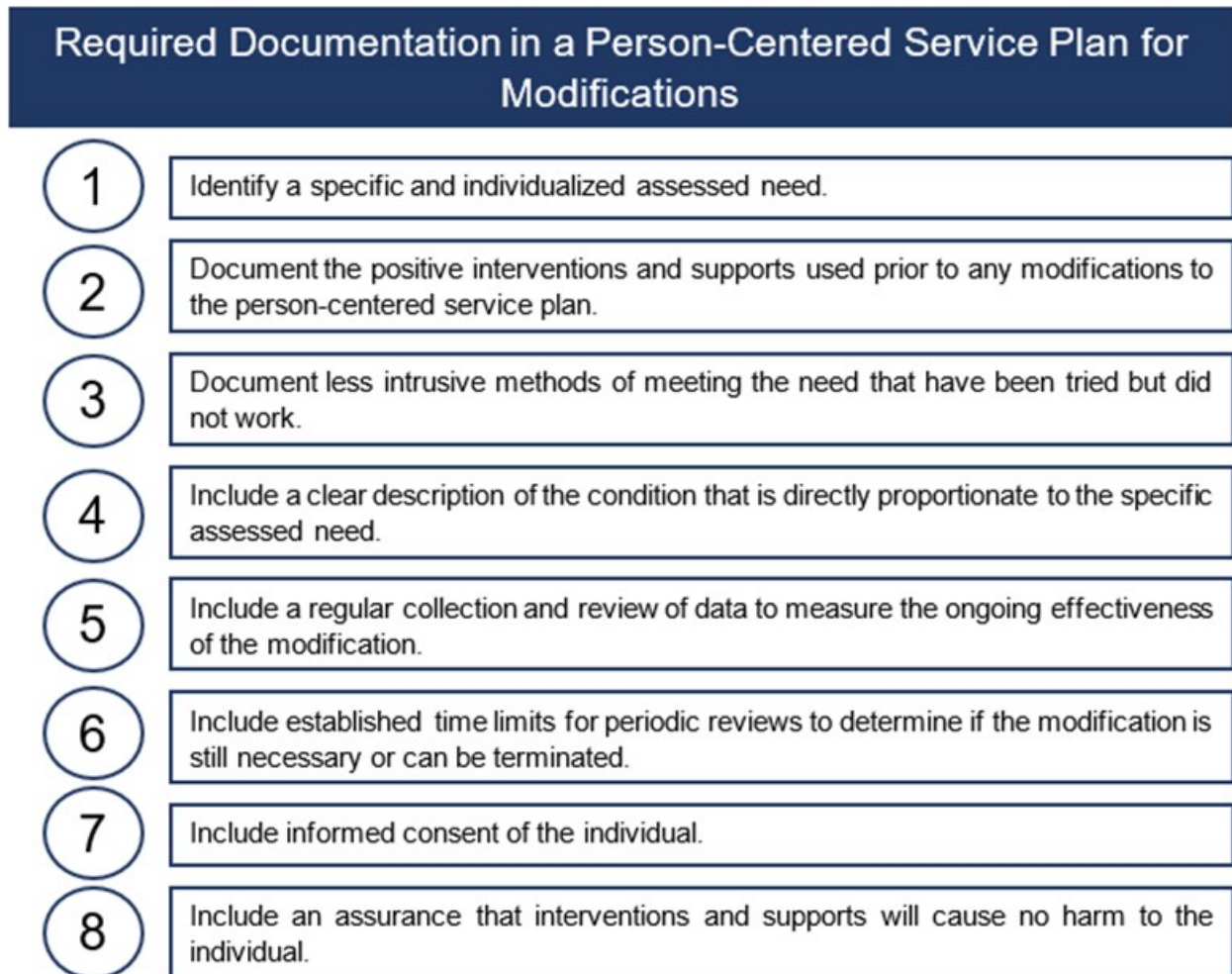


Figure 7. Required documentation in a person-centered service plan for modifications.

HCBS Final Settings Rule Requirements for Community Integration



Historically, people with disabilities have had limited opportunities to engage meaningful community activities and settings. Prior to HCBS, many individuals with disabilities were placed in large congregate institutions with limited or no community access. When HCBS waivers were adopted by states in the early

1980s, individuals receiving waiver services were afforded more opportunities to engage in meaningful residential and non-residential settings that were less restrictive. However, many HCBS waiver recipients still do not have access to the full range of community options available to people without disabilities. The ADA Title II integration mandate and the Department of Justice reinforces that services, programs, and activities should be provided in the most integrated setting possible. In fact, Cullen et al. (1995) suggests that while people with disabilities are being physically located in the community, they are not meaningfully integrated and engaging in the full range of community options. The Final Settings Rule is designed to ensure that the HCBS recipients are provided with opportunities to have meaningful community integration and choice.

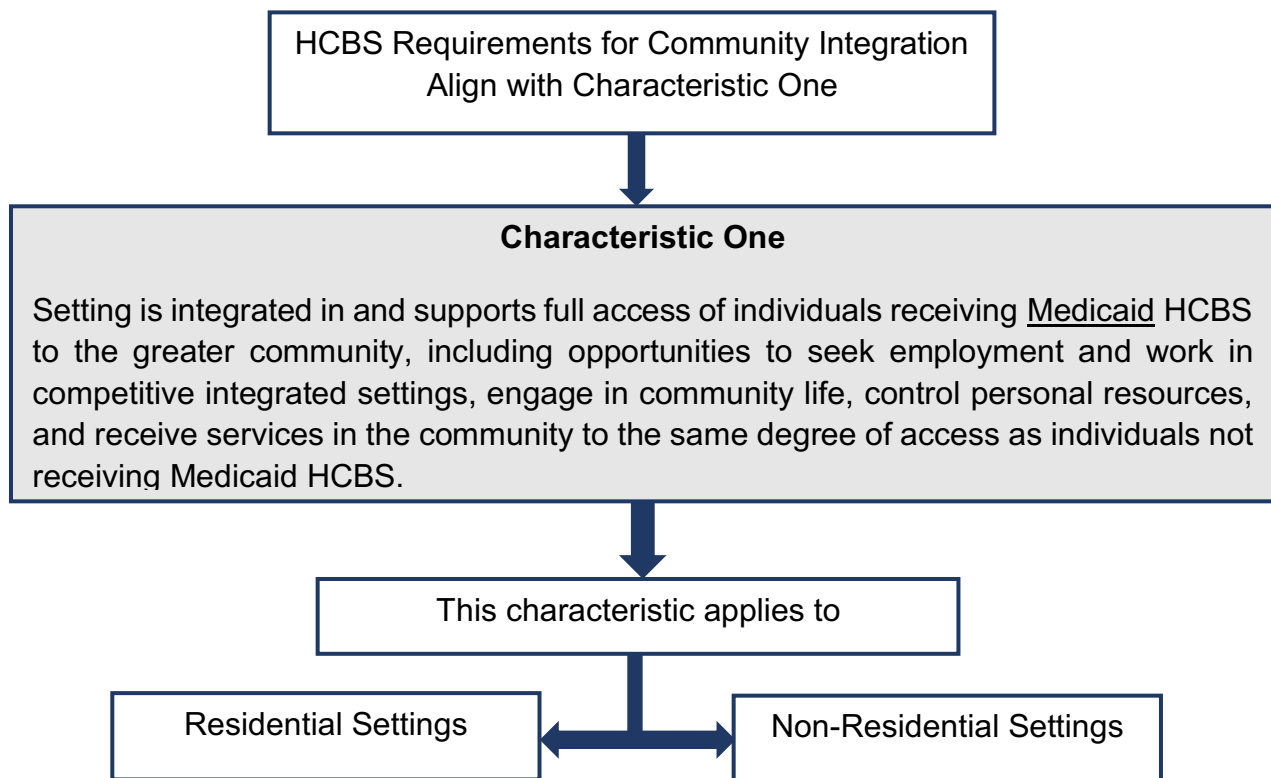


Figure 8. HCBS requirements for community integration.

Considerations for Providers

The CMS provides guidance on community integration for HCBS recipients. Specifically, people who receive waiver services must have access to activities and community resources. Residential providers should ensure individuals have full access to the community and create supports that are not institutional in nature. In the context of residential settings, providers should consider the questions in Figure 9.

Considerations When Developing Services & Supports for Residential Providers

1

Do individuals come and go at will?
Is there a curfew or other requirements for a scheduled return to the setting?

2

Do individuals in the setting have access to public transportation?
Are there bus stops nearby or are taxis available in the area?
Is an accessible van available to transport individuals to appointments, shopping, etc.?
Are bus and other public transportation schedules and telephone numbers posted in a convenient location?
Is training in the use of public transportation facilitated?

3

Does the individual work in an integrated community setting?
If the individual would like to work, is there activity which ensures the option is pursued?

4

Does the individual participate regularly in meaningful nonwork activities in integrated community settings for the period of time desired by the individual?

5

Is the setting based in a location that facilitates integration within the greater community including access to restaurants, businesses, and other residential areas?
The setting should NOT be located in a facility that provides inpatient treatment or is adjacent to a public institution.

Figure 9. Considerations when developing services and supports in residential settings.

Non-residential settings must be integrated and provide opportunities for individuals 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. Figure 10 presents questions non-residential providers should consider when developing services and supports that align with characteristic one.

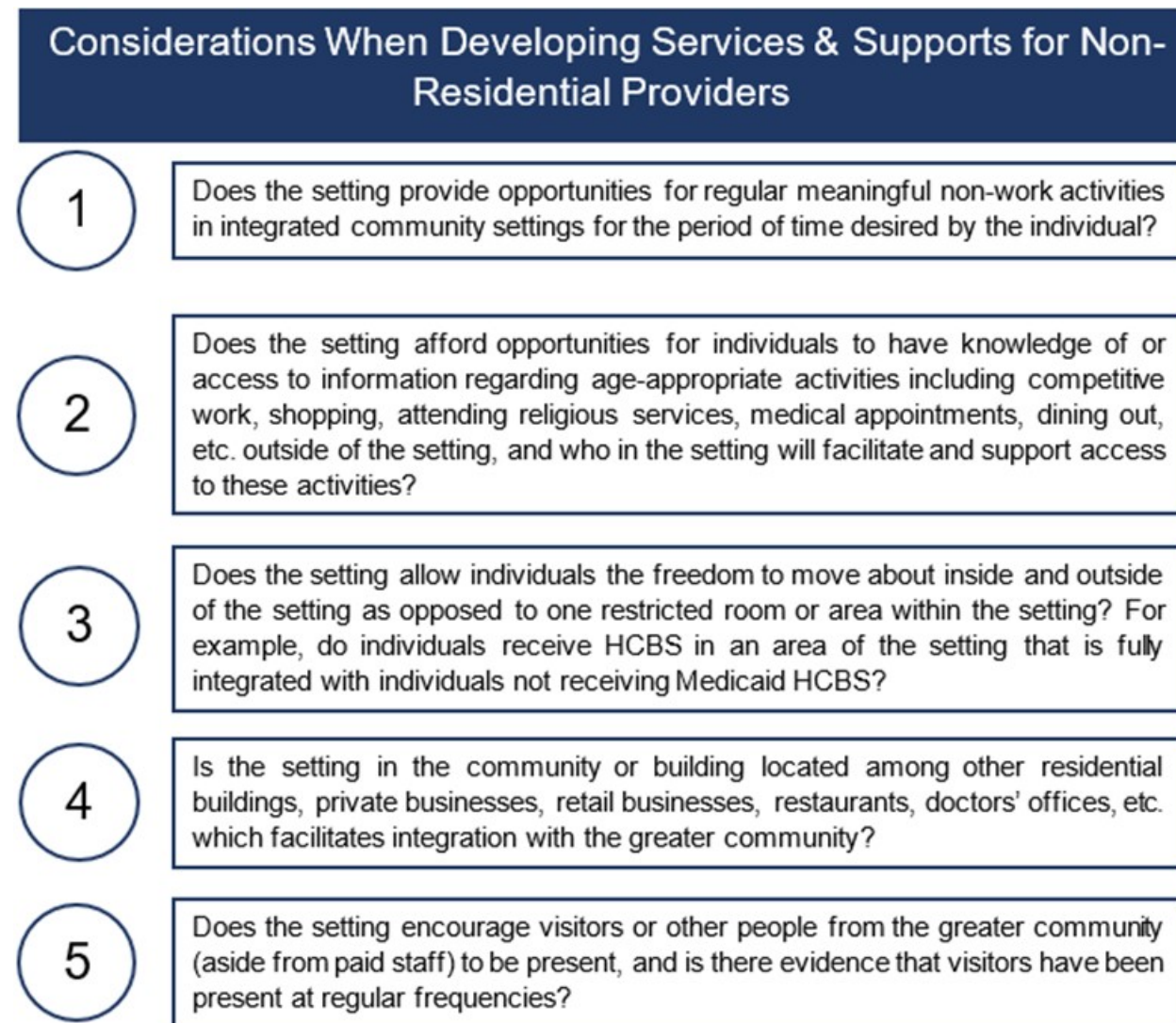


Figure 10. Considerations when developing services and supports for non-residential providers.

Considerations for Providers

The CMS provides additional examples for non-residential providers. In regard to visitors, the CMS suggests providers consider whether (a) visitors greet/acknowledge individuals receiving services with familiarity when they encounter them, (b) visiting hours are unrestricted, and (c) the setting otherwise encourages interaction with the public (for example, as customers in a pre-vocational setting)? In regards to financial supports, when HCBS recipients are in settings where money management is part of the services, providers should examine if the setting facilitates the opportunity for individuals to have a checking or savings account or other means to have access to and control his/her funds. For example, is it clear the individual is not required to sign over his/her paychecks to the provider?

HCBS Requirements for Choice, Autonomy, and Independence



Research suggests people with disabilities, especially those with more significant disabilities, are not always given opportunities to make informed choices (Neely-Barnes, Marcenko, & Weber, 2008a). When individuals with disabilities are provided with opportunities to make informed choices, they are more likely to choose community-based activities and more integrated living arrangements (Davis & Faw, 2002).

Research also suggests when people with disabilities live in smaller living arrangements and make more autonomous choices, they have better quality of life indicators such as protection of individual rights and greater access to the community (Neely-Barnes, Marcenko, Weber, 2008b). The Final Settings Rule also reinforces the notion that full choice, autonomy, and independence are critical to the quality of life for HCBS recipients. The application of the Final Settings Rule requirements for choice, autonomy, and independence apply to both residential and non-residential settings and align with characteristics two, four, and five (see Figure 11).

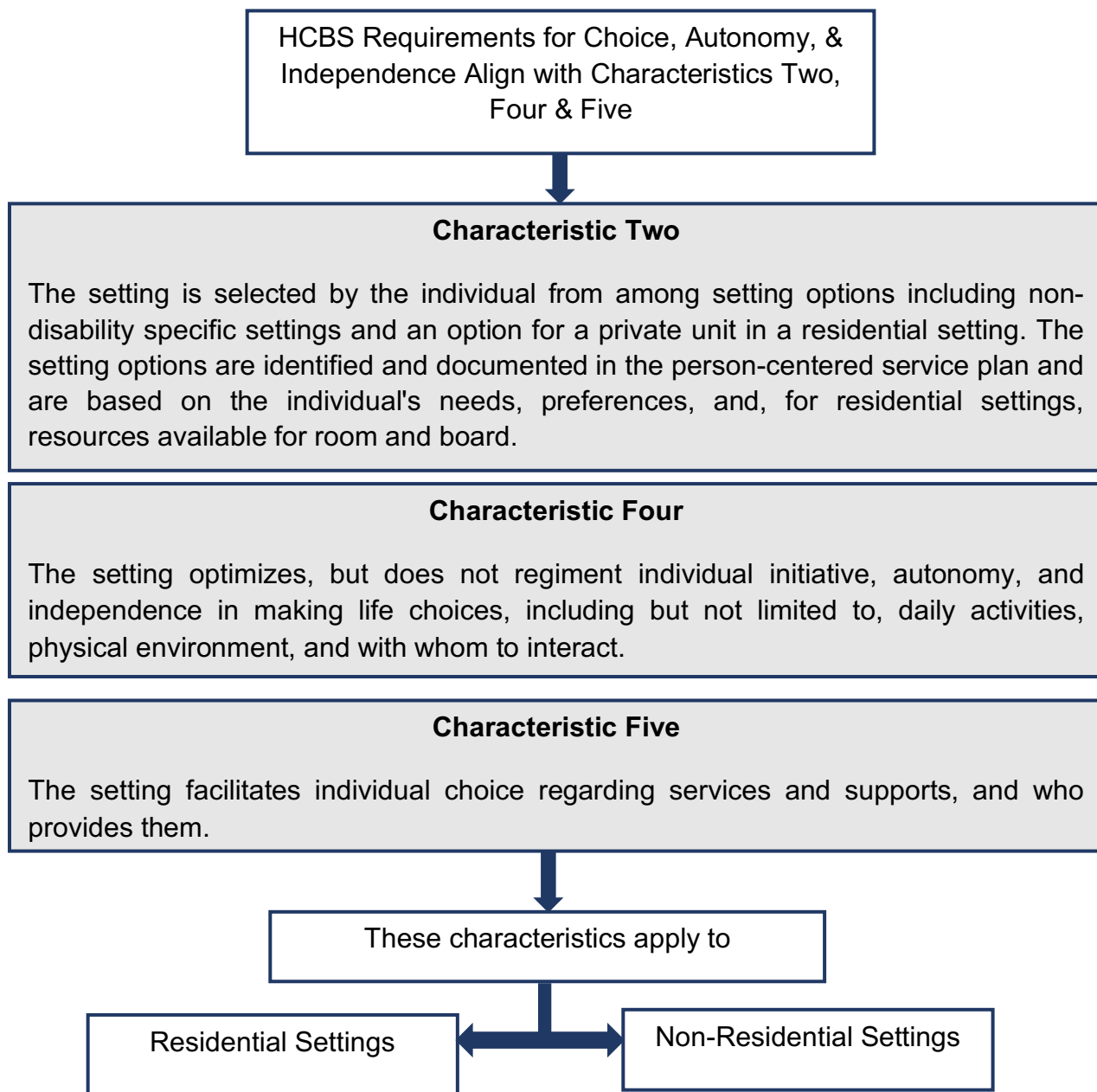


Figure 11. HCBS requirements for choice, autonomy, and independence.

Considerations for Providers

The CMS provides specific guidance for residential and non-residential providers regarding characteristics two, four, and five. In terms of informed choice (characteristic two), the final settings rule indicates the setting should be selected by the HCBS recipient and the setting clearly reflects the person's needs and preferences. The setting should also take steps to not restrict access to community-based activities and programs that are available to people without disabilities. Figure 12 provides additional information about informed choice. In regard to autonomy and independence (characteristic four), both residential and non-residential settings should, among many things, provide opportunities for HCBS recipients to engage in activities and access environments that are based on individual goals and needs. Figure 13 provides specific questions for residential and non-residential providers surrounding autonomy and independence. Characteristic five considers choice regarding services and supports and who provides them. Given this characteristic, HCBS recipients should have opportunities to update and change individual preferences regarding services and supports at different times and they should receive individual support to develop plans supporting their interests and needs.

Considerations Regarding Autonomy and Independence in HCBS Settings

Residential	Does the setting reflect individual needs and preferences and do its policies ensure the informed choice of the individual? Does the setting post or provide information on individual rights?
	Does the individual choose when and what to eat? <ul style="list-style-type: none">• Can the individual request an alternative meal if desired?• Does the individual have a meal at the time and place of his or her choosing?
Non-Residential	Are there gates, Velcro strips, locked doors, fences, or other barriers preventing individuals' entrance to or exit from certain areas of the setting?
	Does the setting afford a variety of meaningful non-work activities that are responsive to the goals, interests, and needs of individuals?
	Does the setting afford opportunities for individuals to choose with whom to do activities in the setting or outside the setting or are individuals assigned only to be with a certain group of people?
	Does the setting allow for individuals to have a meal/snacks at the time and place of their choosing?

Figure 12. Considerations regarding autonomy and independence in HCBS settings.

Considerations Regarding Informed Choice in HCBS Settings

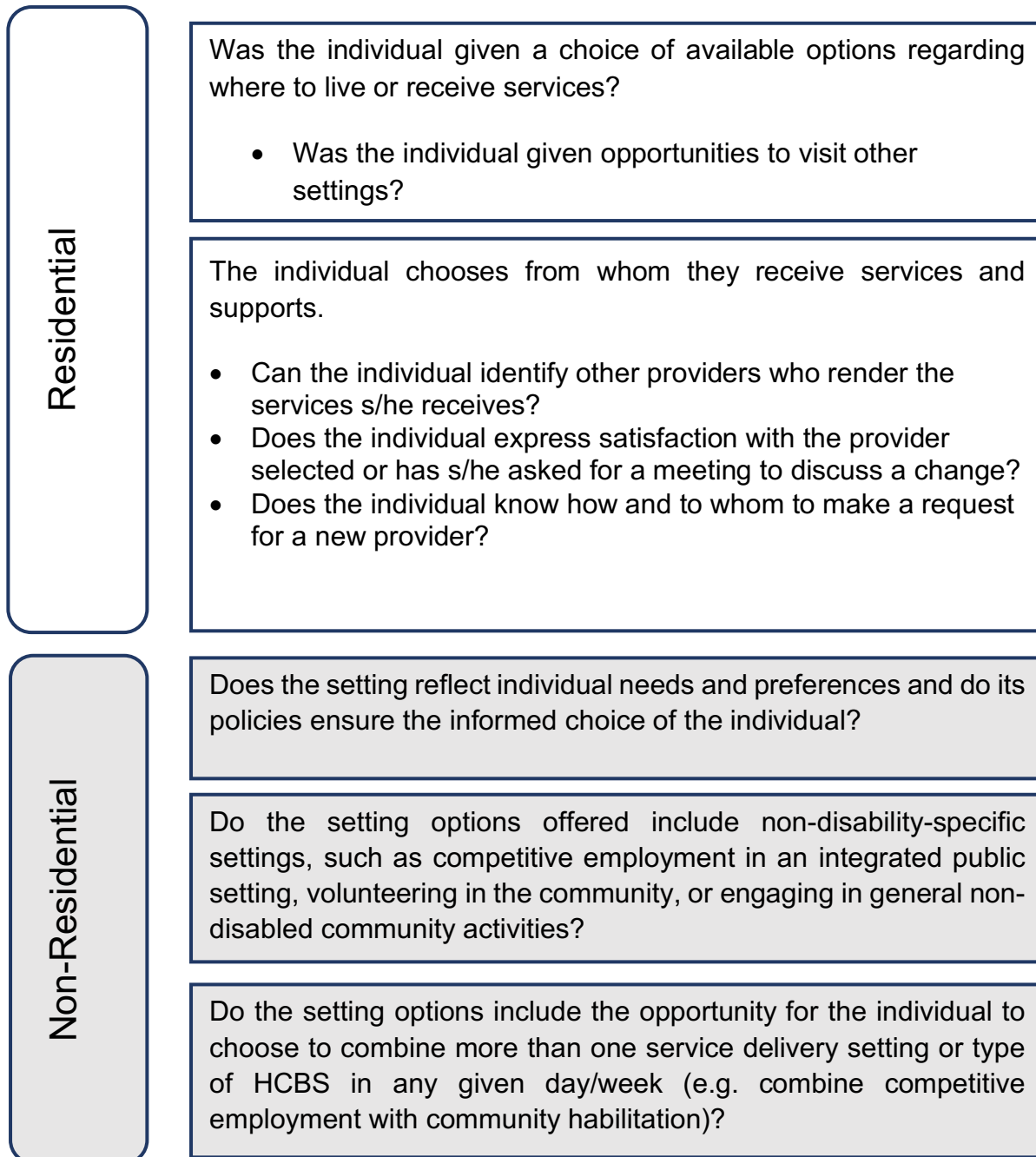


Figure 13. Questions regarding informed choice in HCBS settings.

Privacy, Dignity, Respect, and Freedom from Coercion and Restraint



Privacy, dignity, respect, and freedom from coercion and restraint are characteristics all of us need to in order to maintain a high quality of life, wellbeing, and empowerment. Characteristics three and seven reinforce the value that people with disabilities should receive HCBS in settings that value privacy, dignity, respect, and are free from coercion and restraint (see Figure 14).

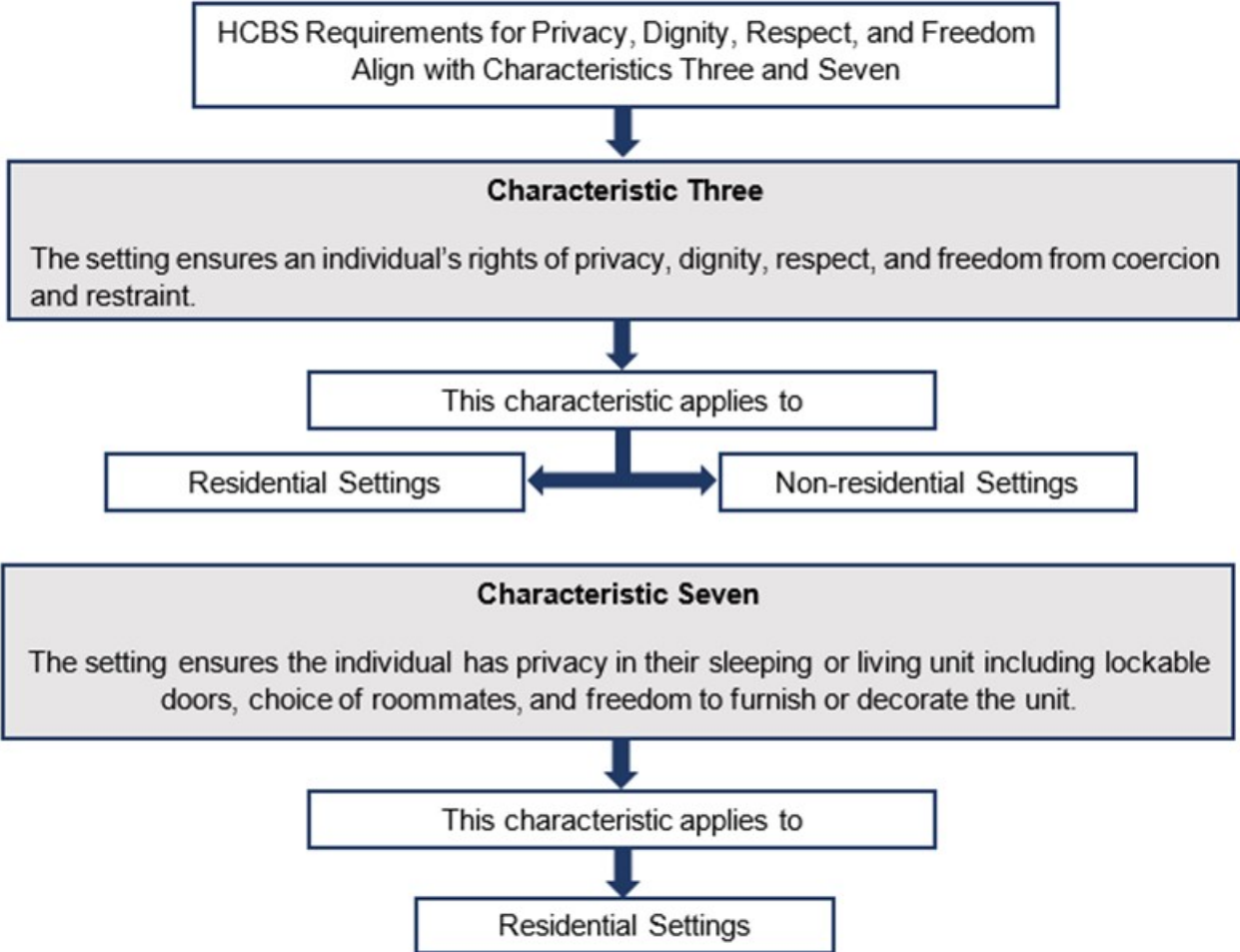


Figure 14. HCBS requirements for privacy, dignity, respect, and freedom.

Considerations for Providers

The CMS provides specific guidance for residential and non-residential providers regarding characteristics three and seven. In regard to rights of privacy, dignity, respect, and freedom from coercion and restraint, settings should train staff about following confidentiality policy and practices.

Considerations Regarding Privacy, Dignity, Respect, and Freedom from Coercion and Restraint

Residential	<p>Individuals have privacy in their living and sleeping space and toileting facility.</p> <ul style="list-style-type: none">• Is the furniture arranged as individuals prefer and does the arrangement assure privacy and comfort?
	<p>Individuals are free from coercion.</p> <ul style="list-style-type: none">• Is the individual comfortable discussing concerns?• Does the individual know the person to contact or the process to make an anonymous complaint?• Can the individual file an anonymous complaint?
Non-Residential	<p>Does the setting support individuals who need assistance with their personal appearance to appear as they desire?</p> <p>Is personal assistance provided in private, as appropriate?</p>
	<p>Does the setting assure staff interact and communicate with individuals respectfully and in a manner in which the person would like to be addressed, while providing assistance during the regular course of daily activities?</p>
	<p>Do setting requirements assure staff do not talk to other staff about an individual(s) in the presence of other persons or in the presence of the individual as if s/he were not present?</p>

Figure 15. Considerations regarding privacy, dignity, respect, and freedom from coercion and restraint settings.

Settings should also stake steps to ensure individual supports and plans address specific behavior needs using the least restrictive strategies that maintain the dignity and rights of the HCBS recipient. Specifically, settings must have a policy that requires the individual and/or representative grant informed consent prior to the use of restraints and/or restrictive interventions and document these interventions in the person-centered service plan. In addition, the setting’s policy should ensure each individual’s supports and plans address behavioral needs and are specific to the individual. Individual plans should not restrict the rights of other individuals receiving support in the same HCBS setting. For example, if one person is restricted from using the refrigerator during certain hours, others in the setting should still be able to access the refrigerator during those times. Finally, the setting should develop and make readily available information about how to make a complaint regarding a rights violation. Figure 15 provides addition guidance for residential and non-residential providers. Characteristic seven applies only to residential settings. Specifically, settings should ensure the tenant has control over his or her privacy and has the option to lock their bedroom door and the front door. Settings should also train staff on when staff can enter a tenant’s room. Unless identified as a modification, staff should only access a tenant’s bedroom or unit to address health and safety concerns and request entry to a tenant’s bedroom or unit by knocking or requesting the tenant’s permission to enter.

Lease Agreements



(see Figure 16).

This provision is designed to ensure rights and protections of HCBS recipients who live in a provider-owned or controlled residence are equal to other community members. To ensure equal protection, providers should develop a signed lease agreement that looks similar or equal to those not receiving HCBS. Characteristic six provides information regarding lease agreements

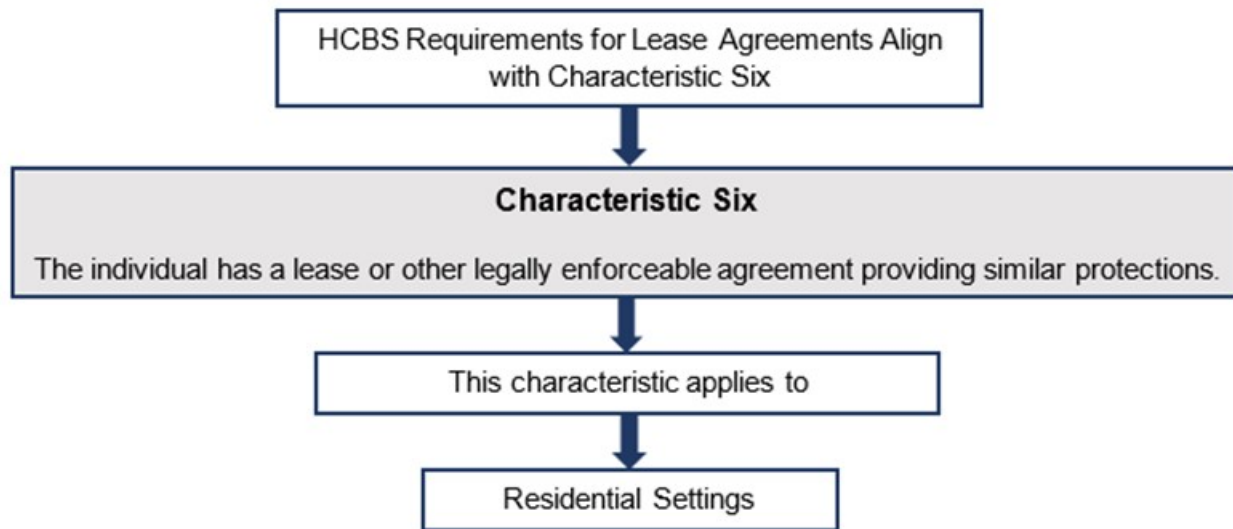


Figure 16. HCBS requirements for lease agreements.

Considerations for Providers

As indicated in characteristic six, residential settings should provide a legally enforceable agreement for the unit or dwelling where the individual resides. CMS outlines a number of questions settings should consider, including:

- Does the individual have a lease or, for settings in which landlord tenant laws do not apply, a written residency agreement?
- Does the individual know his/her rights regarding housing and when s/he could be required to relocate?
- Are individuals protected from eviction and afforded appeal rights in the same manner as all persons in the State who are not receiving Medicaid HCBS?
- Do individuals know their rights regarding housing and when they could be required to relocate?
- Do individuals know how to relocate and request new housing?
- Does the written agreement include language that provides protections to address eviction processes and appeals comparable to those provided under the jurisdiction's landlord tenant laws?

Schedules, Activities, and Access to Food



Promoting choice of schedules and activities is an important component of services and supports for HCBS recipients. Individuals receiving HCBS should be provided with opportunities to control their schedules and engage in meaningful activities. This means HCBS recipients are not required to follow a set schedule of waking, bathing, exercising, etc. The schedule should be based on an individual's preferences and personal responsibilities throughout his or her day. In addition, there should not be restrictions on food including set mealtimes or set mealtime seating arrangements.

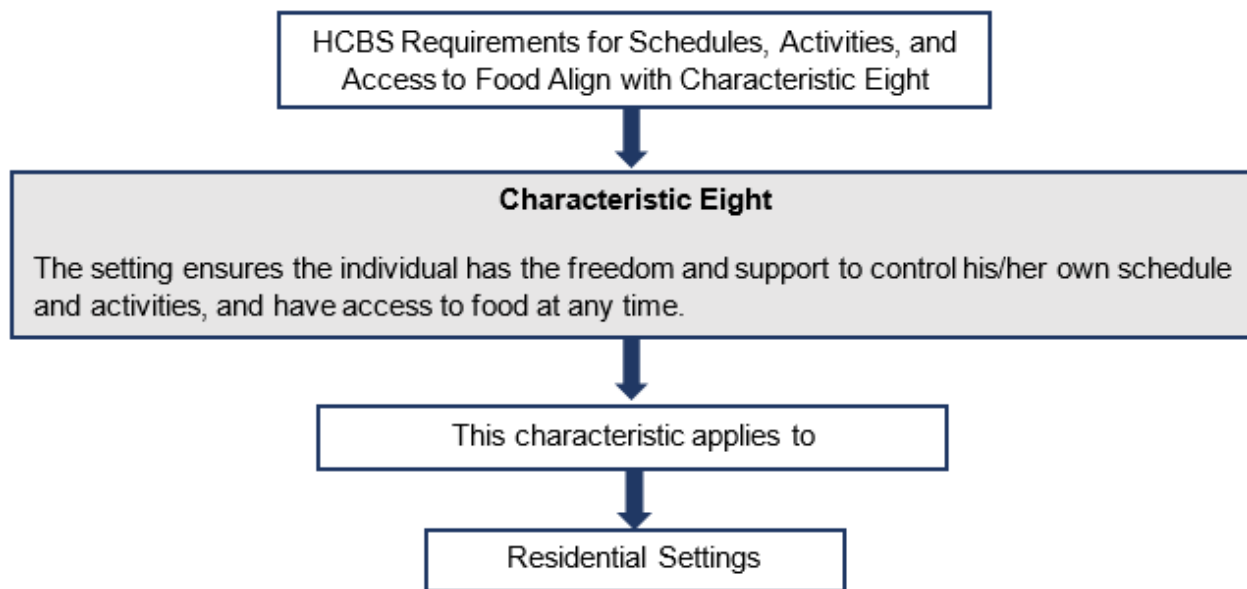


Figure 17. HCBS requirements for schedules, activities, and access to food.

Considerations for Providers

Settings should have plans to support HCBS in planning day-to-day activities and schedules. Figure 18 provides questions to help settings meet the requirements outlined in characteristic eight.

Considerations Regarding Schedules, Activities, and Food

Schedules & Activities	<p>The individual chooses and controls a schedule that meets his/her wishes in accordance with a person-centered plan.</p> <ul style="list-style-type: none">• How is it made clear that the individual is not required to adhere to a set schedule for waking, bathing, eating, exercising, activities, etc.?• Does the individual's schedule vary from others in the same setting?• Does the individual have access to such things as a television, radio, and leisure activities that interest him/her and can s/he schedule such activities at his/her convenience?
Food	<p>Does the individual have a meal at the time and place of his/her choosing?</p> <ul style="list-style-type: none">• Can the individual request an alternative meal if desired?• Are snacks accessible and available anytime?• Does the dining area afford dignity to the diners and are individuals not required to wear bibs or use disposable cutlery, plates and cups?

Figure 18. Considerations regarding schedules, activities, and food.

Visitors



Individuals receiving HCBS should have multiple and meaningful opportunities to develop relationships. Therefore, HCBS recipients may have visitors at any time and in areas that are not limited to visitor meeting areas. This includes private visits with family and friends will not be restricted to visitor meeting areas (see Figure 19).

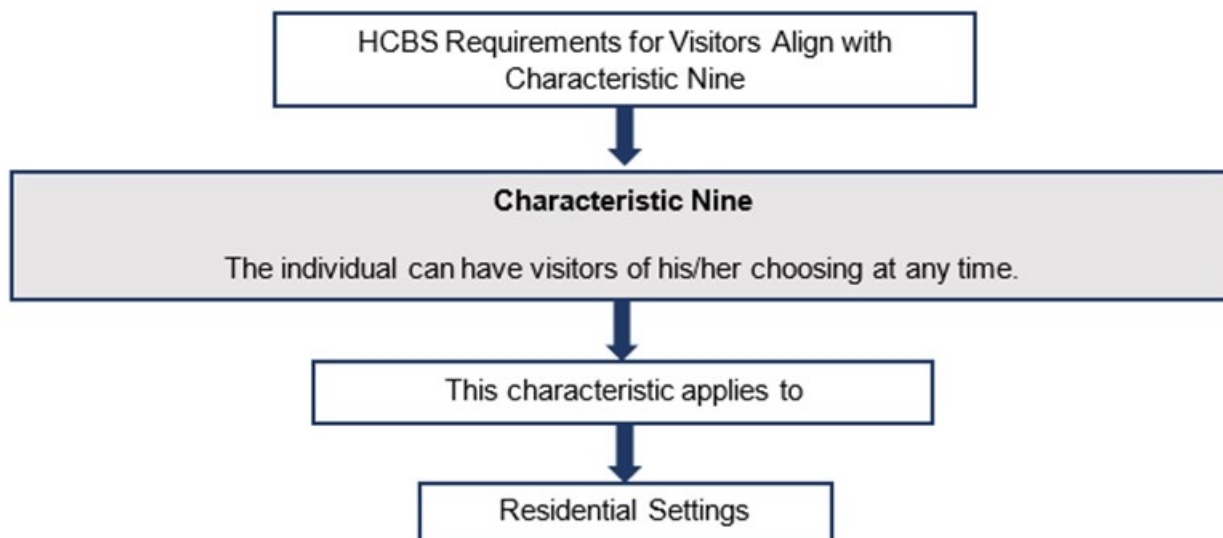


Figure 19. HCBS requirements for visitors.

Considerations for Providers

Characteristic nine ensures HCBS recipients are able to develop meaningful relationships and have visitors in their home. HCBS recipients should have access to unrestricted visitor areas that allow for privacy during visits.

Accessibility



Settings should be physically accessible to HCBS recipients. This means settings should examine environments to determine how the physical setting is meeting the needs of the HCBS recipient. There should be no obstructions that limit mobility in the setting. In addition, the setting must provide full access to common areas such as the kitchen, laundry room, and living area (see Figure 20).

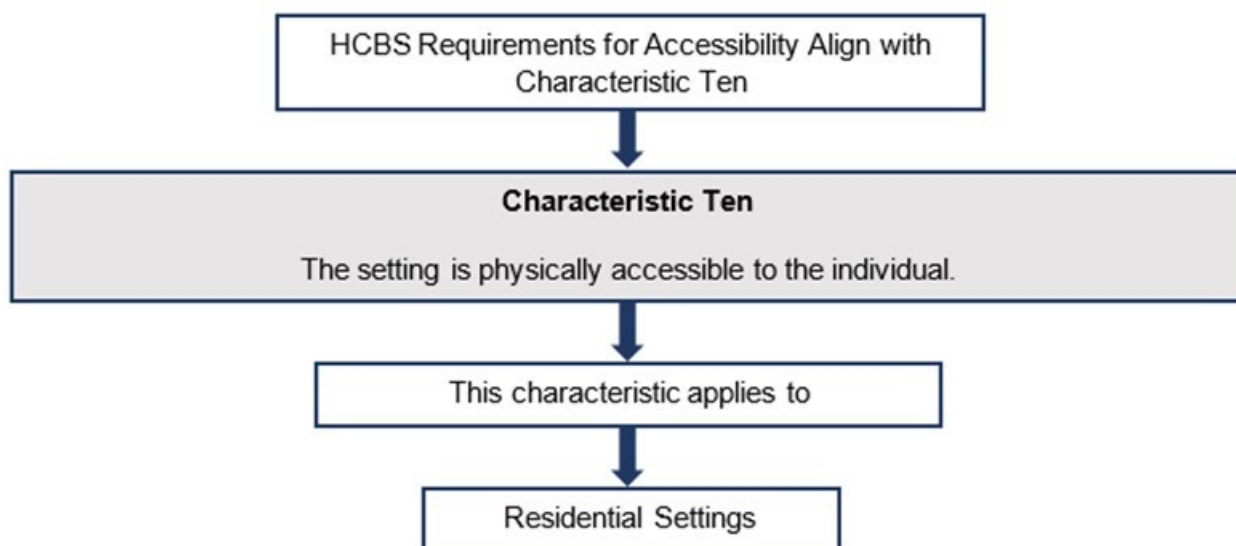


Figure 20. HCBS requirements for accessibility.

Considerations for Providers

Providers should meet with the HCBS recipient to determine individual accessibility needs. In addition, the provider should implement the principles of universal design in their settings. There are seven principles of universal design (Center for Excellence in Universal Design, n.d.), these include: (a) equitable use, (b) flexibility in use, (c) simple and intuitive use, (d) perceptible information, (e) tolerance for error, (f) low physical effort, and (g) size and space for approach and use. Visit <http://universaldesign.ie/What-is-Universal-Design/The-7-Principles/> for a complete discussion about these principles.

Enforcement

HCBS providers should take steps to ensure the setting meets the HCBS settings requirements. Providers should develop procedures to train staff on the provisions of the Final Settings Rule for both non-residential and residential settings (see Figure 21).

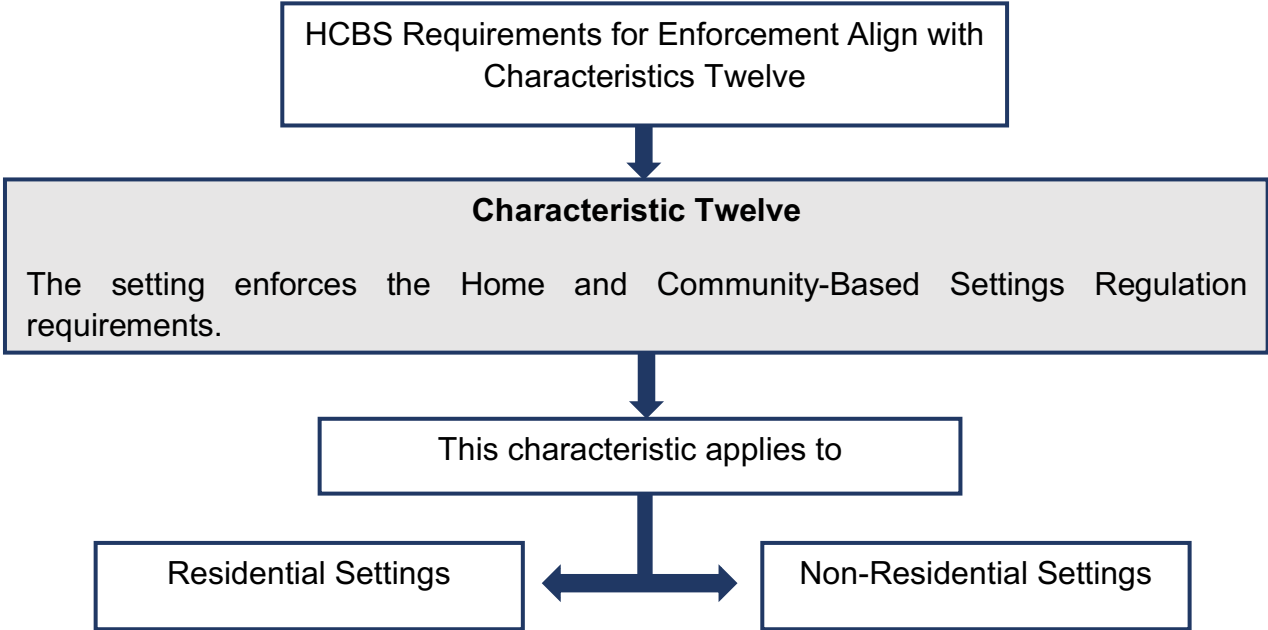


Figure 21. HCBS requirements for enforcement.

Considerations for Providers

Characteristic twelve ensures providers are effectively enforcing the Final Settings Rule. Paid and unpaid staff should receive new hire training and continuing education related to the rights of individuals and individual experience. Policies regarding the Final Settings Rule should be regularly reassessed for compliance and effectiveness and policies outlining individuals' rights and experiences are available when requested.

Resources

Resource	URL	Description
Center for Excellence in Universal Design	http://universaldesign.ie/What-is-Universal-Design/The-7-Principles/	Provides information about the importance and principles of Universal Design
Center for Employment and Inclusion	www.ceiutah.com	Information and Trainings/Webinars related to the HCBS Settings Rule specific to Utah
Disability Law Center	http://disabilitylawcenter.org/hcbs/	The Utah Disability Law Center HCBS page provides information about compliance with the Final Settings Rule
Division of Services for People with Disabilities (DSPD)	https://dspd.utah.gov	The Division of Service for People with Disabilities (DSPD) website, has multiple resources relating to the HCBS Settings Rule
HCBS Coalition	https://hcbsadvocacy.org/learn-about-the-new-rules/	Web page for resources and information about the Final Settings Rule
Legal Information Institute Cornell Law School	https://www.law.cornell.edu/cfr/text/42/441.301	View the Code of Federal Regulation 42 CFR 441.301 – Contents of request for a waiver
Medicaid.gov	https://www.medicaid.gov/medicaid/hcbs/guidance/hcbs-final-regulation/index.html	Information about the Home & Community-Based Services Final Regulation

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