



State of Rhode Island and Providence Plantations
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Division of Developmental Disabilities
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HCBS Final Rule

Guidance for Implementation and Frequently Asked Questions

Part 2

TABLE OF CONTENTS

I.	INTRODUCTION.....	2
II.	REQUIREMENTS FOR ALL SETTINGS	
	Setting Selection.....	2
	The Rights Rule.....	4
	Autonomy.....	8
	Choice in Services and Supports.....	9

I. INTRODUCTION

How does service delivery need to change?

If you are a service provider supporting multiple consumers in one location, the services being provided at that location must not isolate individuals from the community. The Final Rule mandates that settings be integrated and support full access to the community. As a provider, you may need to modify where and how your services are delivered to meet the HCBS Final Rule. Policies and program designs may need to be updated, and staff training may be necessary to assure understanding of the new standards.

II. REQUIREMENTS FOR ALL SETTINGS

Setting Selection

The Final Rule specifies that a basic quality of an HCBS setting is that it is chosen by the participant as a place to receive service(s). If a participant has not freely chosen a setting, then HCBS funding to that setting is at risk. This general requirement of setting selection applies to all HCBS provider settings, and it ensures that participants are aware of their options and have an opportunity to select the settings where they receive HCBS services. In the case of residential settings, the Rule also requires that relevant information about the participant's selection of their current residence be documented in the participant's ISP.

Participants' options must not be limited to settings which are "disability-specific" (for example, a setting which is only for people with autism, or only for people with disabilities). Participants are free to choose such a setting, but they also are free to choose settings which are **not** disability-specific. The principle of setting selection, then, requires that the options presented to participants include settings for people with varying disabilities and/or people without disabilities.

The setting selection requirement also means that participants can choose service settings independently of their residential setting choice. Residential settings provide certain services that are inherent in those settings, but a participant must not be required to choose their residential provider's day program, for example, as a condition of living in the residence. Similarly, a participant in a shared living arrangement (SLA) is free to choose a day service setting which meets their needs and desires, even if that choice entails a change in the participant's daily schedule. In short, a participant has the freedom to elect, receive, and deny services without risk of eviction from their residence.

What if a participant would receive the best support in a disability-specific setting, but they are choosing a different setting?

Participants need to make informed choices when they are selecting service settings. To do this, they need to know **all** their options and the potential benefits and drawbacks of those options. Therefore, the first step is to make sure the participant is well-informed. Visiting settings is a very important way of getting information, so the participant should visit as many setting options as possible, including disability-specific settings if the participant desires. In the end, however, the choice of setting is the participant's.

The point of the Final Rule regarding disability-specific settings is that participants should not be "assigned" to such a setting based only on diagnosis or type of disability. Participants must have other options, and those options must include settings where people of varying disabilities, or no disabilities at all, receive services.

If a participant has a Shared Living Arrangement, can they choose an integrated day setting with a variable daily schedule?

Yes. A participant is free to choose day services that meet their needs, desires, and preferences, even if those services create challenges in daily scheduling at their residence. Providers and participants are encouraged to work together and with the participant's Social Case Worker and Support Coordinator to address any scheduling challenges and work toward a resolution that aligns with the participant's interests.

Sample policy language

Policy: Setting selection

(Provider) will encourage participants to ask questions about their setting options, both before and after they accept (provider's) service(s).

(Provider) will encourage participants to visit settings as part of their informed decision-making process, both before and after they accept (provider's) service(s).

(Provider) will provide participants and their support teams with regular opportunities for feedback regarding settings, services, and service providers.

(Provider) will regularly inform participants and their support teams how to request a different setting and/or change current services or supports.

The Rights Rule

Another basic quality of an HCBS setting is participants' rights of privacy, dignity, and respect, accompanied by freedom from coercion and restraint. Any violations of these rights and freedom jeopardize the setting's HCBS status and funding, in addition to the ethical and regulatory implications of the violations.

The right to privacy extends to all participants, regardless of their communication abilities or intellectual function. Preserving the privacy of participants, who naturally have varying needs and abilities, requires individualized approaches and supports. The tendency to overlook the right to privacy of participants with more significant needs can develop over time, since these participants often cannot verbalize their privacy needs. All measures must be taken to ensure that this does not happen.

Physical privacy during personal care, privacy of personal health information, privacy in personal living quarters, and privacy in daily communication are all included in the general right to privacy.

The rights to dignity and respect, as well as the definitions of dignity and respect, are similar. Dignity is defined as the state of being worthy of honor. Respect is defined as due regard for the feelings, wishes, rights, or traditions of others. The rights to dignity and respect must be upheld in all settings.

Participants are treated with dignity and respect when their opinions and contributions are taken seriously; when agency staff speak to them as equal partners and ask them for input; and when their requests for services or supports are addressed directly and honestly and accommodated whenever possible. An important question that should be in the minds of every agency staff person in every interaction is whether that interaction is dignified and respectful to the participant.

In the Final Rule, the rights to privacy, dignity and respect are accompanied by freedom from coercion and restraint. Coercion is defined as using threats, intimidation, and/or authority to force compliance from a person, even when it is against the person's best interest. Restraint is defined as restricting the movement of the whole or a portion of a person's body to control their physical activities. Restraint comes in different forms, such as physical and chemical.

The Final Rule forbids coercion and restraint in HCBS settings, except specific restraints that are used as part of an approved behavioral support plan. The process for instituting such a plan is set forth in the RI Rules and Regulations for Developmental Disability Organizations (section 1.12.5ff).

If a participant is nonverbal or has limited expressive or receptive communication abilities, how does the rights rule apply to them?

The rights rule applies to all participants completely and equally, regardless of communication or cognitive ability. If a participant is nonverbal or has limited communication abilities, those who interact with them must take extra measures or do things differently to respect these rights. For example, closely observing the participant's body language or other physical cues is necessary to determine if they might be uncomfortable in the interaction. For those participants who have legal guardians, the rights of privacy, dignity, and respect and freedom from coercion and restraint are assumed by the guardian on behalf of the participant, and the guardian must ensure that these rights are respected.

If a participant is abusive to staff persons or otherwise violates their rights, how should the staff respond?

The staff should respond in the same way they respond to every other participant – with privacy, dignity, and respect, and without coercion or restraint. However, as stated above, behavioral support plans which follow regulatory requirements and may include restraints are sometimes necessary to preserve physical and emotional safety for all involved. Such plans are strategies to promote and protect the well-being and rights of participants by providing a structured response to prevent further abuse. Respecting an abusive participant's rights can be very challenging at times, but it is required of everyone who has contact with the participant.

Can participant rights be restricted in behavioral support plans?

Generally, no. The Rhode Island Rules and Regulations for DDOs require that all behavioral supports and treatment conform to and abide by Rhode Island laws regarding participant rights.

The Rules and Regulations identify several ways that general behavioral supports must respect participant rights, such as the requirements that:

- supports designed to reduce the frequency of inappropriate behaviors are used only in conjunction with positive supports designed to strengthen adaptive and appropriate behaviors;
- supports are provided according to behavioral intervention policies and procedures;
- the development of supports is informed by the results of functional behavioral assessments.

In the case of behavioral support **plans**, participant rights are preserved in several ways as well. These include:

- the decision to develop a plan is made by the participant and their support team
- the plan is developed only by a licensed clinician and is based on assessed clinical needs
- a plan which is not written must not be administered
- written consent by the participant or responsible party is given before the plan is administered, and annually thereafter.

The Rules and Regulations stipulate that behavioral support plans which restrict a participant’s rights “shall be used only to address specifically identified extraordinarily difficult or dangerous behavioral problems that significantly interfere with appropriate behavior and/or the learning of appropriate and useful skills, and/or that have seriously harmed or are likely to seriously harm, the individual or others.”

The Rules and Regulations further stipulate that restrictive interventions will be allowed “only after a review and approval by clinicians, families, guardians, and the Human Rights Committee.” This process must ensure that “clinicians have exhausted other less restrictive interventions” and that “the likely benefit of the procedure to the participant outweighs its apparent risk of life safety.”

Some restrictive interventions are prohibited under any circumstances. These include:

- using law enforcement in lieu of a clinically approved therapeutic emergency intervention or behavioral treatment program
- behavioral interventions used for the convenience of the staff
- behavioral interventions used for any reason except emergency protocol.

What about the right to privacy of “personal health information” under HIPAA?

Personal health information (PHI) has two basic components – an individual’s identifying information (such as name or SSN, but also other information that is a reasonable basis for identifying an individual) and health information. When identifying information is linked to health information, it is considered PHI. For example, “John Doe has high blood pressure” is PHI.

Health information, according to the U.S. Department of Health and Human Services, relates to:

- 1) the individual’s past, present, or future physical or mental health or condition;
- 2) the provision of healthcare to the individual; or
- 3) the past, present, or future payment for the provision of healthcare to the individual.

(<https://www.hhs.gov/hipaa/for-professionals/privacy/laws-regulations/index.html>)

PHI must be kept private and must not be disclosed except for specific reasons and in specific circumstances. Information regarding a participant's intellectual or developmental disability is considered PHI.

For more guidance about PHI and HIPAA, please visit the above website.

Sample policy language

Policy: Participant rights

(Provider) will ensure all participants' rights of privacy, dignity, and respect and freedom from coercion and restraint at all times. (Provider) will utilize restraints only as a last resort; only as part of a written and approved behavioral support plan; and only in accordance with Rhode Island Licensing and Developmental Disability Organization regulations.

Each participant served by (provider) will be informed of their rights in a way they understand.

Staff of (provider) will discuss a participant's personal and/or health information only in private and only for the purposes of providing support or treatment to the participant.

All participants at (provider) will have access to a telephone to make and receive private calls and to personal communication devices for private texts, email, or other personal communication.

All mail addressed to a participant of (provider) will be delivered to the participant's living quarters unopened. (Provider) staff will assist the participant with opening, reading, or replying to mail only when the participant has requested this assistance.

Participants of (provider) will have access to spaces for private conversations and/or spending time alone, when desired by the participant.

(Provider) will support participants' choices and preferences regarding their personal appearance, including but not limited to clothing and hairstyle, provided these choices and preferences preserve basic personal hygiene and safety.

Note: The above policies are only a sampling and are based upon the HCBS Final Rule specifically. Providers are responsible for ensuring that their policies are consistent with both the HCBS Final Rule and with the participant rights identified in section 1.26 of the Rhode Island Licensing regulations. Those regulations are found at <https://rules.sos.ri.gov/regulations/part/212-10-00-1>.

Autonomy

Another basic quality of an HCBS setting is that it “optimizes, but does not regiment, individual initiative, autonomy, and independence in making life choices....” Life choices include but are not limited to choices of daily activities, physical environment, and with whom to interact. Choice of daily activities and with whom to interact are self-explanatory; choice of physical environment refers to the freedom to go places of one’s choosing.

“Optimizes” is a key word in the above statement. The setting optimizes participants’ autonomy by intentionally creating an environment without restrictions on or control of participants’ decision-making, as a matter of course. When restrictions or control are necessary, they are instituted only as a last resort and only according to regulations and applicable laws (for example, legal guardianship laws).

Optimizing, and not regimenting, a participant’s autonomy often leads to a higher level of trust between provider and participant. Increased trust, in turn, often leads to better outcomes in achievement of participants’ goals.

How can a participant’s autonomy be optimized when serious safety concerns exist?

The point of the Final Rule regarding autonomy is that participants must be afforded autonomy as a basic freedom, like anyone else. When the exercise of autonomy creates serious safety concerns for the participant or others, then the participant may lack the safety awareness and self-preservation skills that others possess. In that case, supports are needed in that area. However, those supports must be provided **only to the degree that they are necessary** to prevent serious harm. In that way, autonomy is optimized.

What about participants who have criminal histories or propensities?

The same point applies to those participants. Supports or restrictions must be provided only to the degree that they are necessary, and thereby autonomy is optimized. When a participant has legal restriction(s) that have been imposed by a court of law, those restrictions are necessary for the participant. The participant’s autonomy is still optimized even when legal restrictions which are necessary for the participant are enforced.

Do the choices to marry and have children fall within the life choices being discussed here?

Yes, those choices are included. They are important examples of life choices. However, like anyone else, a participant needs to be informed and, if necessary, counseled in making those life choices. Presenting the participant with resource ideas and suggesting trusted individuals

for obtaining that information and counseling are ways that a provider can optimize the participant's autonomy.

Does autonomy mean that the participant should be allowed to do whatever they want?

Essentially, yes. Autonomy, however, does not preclude a participant from following rules established by their communities or living with the natural consequences of their choices and behavior. The role of the provider is to guide the participant in exercising their autonomy in beneficial ways, focusing upon the participant's goals, strengths, and needs.

Sample policy language

Policy: Participant autonomy

(Provider) will optimize participants' autonomy in making life choices by encouraging participants to make their own decisions whenever possible. Life choices include, but are not limited to, choices of daily activities, physical environment, and with whom to interact.

(Provider) will support participants in making their own decisions by providing information and guidance, suggesting resources, and facilitating access to the community and to natural supports.

(Provider) will preserve participant autonomy in situations in which others are attempting to make decisions for participants without legal authority to do so.

(Provider) will give priority to a participant's personal preferences over a guardian's or other support person's preferences, unless the participant's preferences pose a documented, serious risk to the participant's basic health or safety.

Choice in Services and Supports

Another basic quality of an HCBS setting is that it "facilitates individual choice regarding services and supports, and who provides them." The role of the provider is to **facilitate** choice, as opposed to **making** choices about services and supports on behalf of the participant. It is sometimes very easy to make these choices on behalf of participants without thinking about it. In the writing of an ISP, for example, some services and supports are added to the plan almost automatically, because the participant "obviously" needs that support. When an ISP is written in that way, the participant's choice and voice are lost.

One way to facilitate choice of services and supports is to identify options to the participant and explain them when necessary. Creative thinking and identifying multiple options are important in this process. When a participant has options, they have a greater sense of control in their services and supports, and, as a result, they often have better outcomes. In addition, identifying options is a way of honoring the participant's rights to dignity and respect.

The participant must be given choice about services and supports, but also about *who provides* the services and supports. "Who" refers to agencies as well as individual staff members. If a participant feels uncomfortable around a staff member, or if they prefer direct support professionals of only one gender (such as "women only"), those choices must be fulfilled whenever possible. Also, if a participant chooses natural (unpaid) support persons for all or part of their support, and the support persons are committed to the plan as well, those choices are just as valid as the choice of paid staff.

What if a participant is making a choice about a provider or staff person that is based on inaccurate information or a misunderstanding of the options? The provider's role is to facilitate choice, which includes providing accurate information or an alternative perspective on the options. The provider should not hesitate to provide information or perspective to the participant, assuming the participant is receptive to it. In the end, however, the choice is the participant's.

What if a participant is unable to make or communicate choices?

Again, the provider's role is one of facilitation. If the participant has a legal guardian, the provider should give the guardian as many options as possible and encourage the guardian to identify options on their own. If the participant does not have a guardian, services and supports which are consistent with choices the participant has made in the past or which are aligned with known interests or preferences should be provided. Whether the participant has a guardian or not, their support team always should be looking for any indication from the participant that they are satisfied or dissatisfied with a service or support.

What if a participant is making a choice that puts them at risk for harm?

While most choices of services or supports do not significantly affect a participant's risk for harm, some choices do. For example, a participant who lacks basic safety skills in the community but chooses to learn how to use public transportation independently may be at increased risk for harm. An appropriate provider response would be to identify other options and provide information and perspective, as discussed above. If the participant is not interested in other options, then the provider should initiate a conversation about risk mitigation. How can the risk involved in that service or support be reduced? The provider

should give the participant as much responsibility as possible in identifying ways to reduce the risk and should involve other support team members in the planning process if the participant desires.

It is important to recognize that the choice of a service or support must be distinguished from a general life choice which is inherently risky. For some general life choices, no amount of negotiation or planning will reduce the risk to an “acceptable” level. For example, a participant who chooses to engage in legal gambling has the freedom to make that choice, despite the financial risks. A participant’s support team may be adamantly opposed to a participant’s life choice, but in the end, the participant’s freedom to make such a choice must be respected.

What should be done if a participant’s choice of support person or gender of support person cannot be accommodated at the time?

The first response should be to offer help to the participant in identifying other acceptable options. The participant, however, should take the lead as much as possible. Considering natural supports would be important in identifying options. As soon as the support person of choice is available, the provider is responsible for honoring the participant’s choice. In cases where the choice is not just a preference, but a requirement based on a behavior plan or risk, the provider needs to ensure that procedures are in place to accommodate the need.

Sample policy language

Policy: Choice in services and supports

(Provider) will facilitate participants’ choice of services and supports by providing information and guidance to participants; by identifying viable options with the participant; and by offering the provider’s perspective, if desired, to assist the participant in making an informed choice.

For those participants with legal guardians or other legal decision-makers, (provider) will facilitate choice of services and supports by the legal decision-maker in the same manner as by a participant with no legal decision-maker.

For those participants who are unable to make or communicate choices about services or supports and have no legal guardian, other legal decision-maker, or advocate, (provider) will provide services and supports that are aligned with the participant’s history of chosen services and with known interests and preferences.

For all participants, (provider) will accommodate requests or preferences for particular support persons or a particular gender of support person as much as possible. If it is not possible to

accommodate the participant's request or preference at a given time, other options will be identified with the participant to assist them in making a choice.

If a participant chooses a service or support that would significantly increase their risk for harm, (provider) will assist the participant to identify other service or support options. If no other option is desired by the participant, (provider) will engage the participant in planning risk mitigation strategies which are acceptable to the participant and their support team.

If a participant expresses a desire to receive services or supports from a different provider, (provider) will assist the participant by facilitating the choice of a different provider to the extent desired by the participant.