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By e-mail: Elizabeth.Shelov@ohhs.ri.gov
July 25, 2018

Eric J. Beane, Secretary
Executive Office of Health and Human Services
Medicaid Policy Office
Virks Building, Room
315 3 West Road
Cranston, RI 02920

Attn: Elizabeth Shelov

Re: Comments on Proposed Rule 210-RICHR 50-10-1, Medicaid Long-Term Services and Supports: Home and Community-Based Services (HCBS)

Dear Secretary Beane:

On behalf of the Rhode Island Disability Law Center, Inc. (RIDLC) I am submitting the following comments regarding the above-referenced EOHHS' proposed rule. RIDLC is the federally funded non-profit law office designated as Rhode Island's protection and advocacy agency for individuals with disabilities in Rhode Island. As such, we have a strong appreciation of, and interest in, the state Medicaid agency's provision of long-term care services, especially home and community-based services (HCBS). For many Rhode Islanders with disabilities, HCBS are critical to maintaining their ability to live inclusively in the community.

Our comments follow in the order of the proposed rule's sections.

Section 1.3 Definitions

Under "HCBS living arrangement" there is a reference to a "supportive care residence." That term is not defined in this rule. It's not clear whether this is a reference the term used in R.I. Gen. Laws § 23-17.4-1 et seq. Currently, the Department of Health does not appear to be licensing programs pursuant to that statute. If that is the meaning, absent licensing, the reference should not be included in this regulation

EOHHS Response: Added a citation to this section; The definition is related to the SSP (State Supplemental Program) located in R.I. Gen. Laws §§ 40-8.13-12 and 40-8.9-9(j)(1). It is also defined in the rule at § 1.6(4) of this Part.

Section 1.5 Person-Centered Planning

We appreciate the State's inclusion of this section, which reflects important federal policy regarding Person-Centered Planning found within CMS' HCBS rule. 79 Fed. Reg. 2948 (January 16, 2014).

This section tracks many of the provisions of the federal rule on the Person-Centered Planning Process, but omits some important language on individual direction and rights. For example:

- Federal law requires direction by the individual, not a family member, unless the family member has been given decision-making authority pursuant to state law (e.g. guardianship over medical decision-making). See for e.g., 42 C.F.R. § 441.301 (c)(1) " The *individual will lead the person-centered planning process where possible. The individual's representative should have a participatory role, as needed and as defined by the individual,* unless State law confers decision-making authority to the legal representative."

EOHHS Response: Added the suggested language

- To clarify what it means for planning to occur "at the convenience of the applicant/beneficiary," as stated in § 1.5.1 b., the federal rule language "at times and locations of convenience to the individual" should be substituted.

EOHHS Response: Added the suggested language

- Resolving disagreements about services through consensus building as stated in § 1.5.1 d, may conflict with the federal rule's clear statement that the process should be *led* by the individual. If the individual disagrees with a proposed service, he or she should be provided with any information to help make an informed choice, etc. including information about risk (as stated in § 1.5.l h).

EOHHS Response: Added "led by applicant/beneficiary"

- "Informed" should be inserted after "offer" and before "choice" in § 1.5.1 d. "Informed choice" has a specific legal meaning, which includes providing all relevant information needed to make an informed decision.

EOHHS Response: Done

- Missing from the list of plan contents in § 1.5.2 are federal requirements for the plan to: o 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;

  EOHHS Response: Added this text

- Identify the individual and/or entity responsible for monitoring the plan;
  EOHHS Response: Declined to accept this suggestion

- Be finalized and agreed to, with the informed consent of the individual in writing, and signed by all individuals and providers responsible for its implementation; and
  EOHHS Response: Located in § 1.5.2 of this Part; no need to add lines 6 - 12

- Be distributed to the individual and other people involved in the plan. *See for e.g.,* 42 C.F.R. § 441.301(c)(2) (vii) -(x).

These missing provisions need to be added to the proposed rule.

Section 1.7 Limitations on Availability of Medicaid HCBS

The existing § 1115 waiver permits waiver of the reasonable promptness provisions of the federal Medicaid act, in order to impose waiting lists for HCBS waiver-like services. Inclusion of the exception for persons whose health or safety is in immediate risk is an important provision. Additionally, EOHHS should include a provision in this rule ensuring that individuals seeking services who are placed on any waiting list, are advised of their status (i.e. expected wait time), and kept updated about that status. Knowing the timeframe of availability of HCBS services, will at least enable individuals to plan and make important life choices. EOHHS should also include a provision providing for public notice of the existence of any waiting list, for example, by posting notice on its website.

As CMS generally indicates, any limitations on the provision of HCBS do not exempt the state from compliance with its obligations under *Olmstead v. L.C.,* 527 U.S. 581 (1999). Rhode Island needs to maintain and continue to build its HCBS capacity in order to meet *Olmstead* requirements.

EOHHS Response: Added the language as suggested

Section 1.7.2 Limitations on ICF/I-DD Level of Care for Persons with Developmental Disabilities

Within subsection A.1, there is a reference to ICF/I-DD being generally unavailable in Rhode Island, so that individuals with I-DD who meet the highest need, may need to be placed in a nursing facility or long-term care hospital on an interim basis, because these institutions would "provide the same or more robust service array." Such an assertion is highly unlikely to be true. As the state acknowledges in another proposed rule on "Institutional Care," "[t]here is no exhaustive list of required Medicaid services in the NF [nursing facility] benefit" (see proposed 50-05-01, §1.5 B), unlike the ICF/I-DD, which "is the most comprehensive benefit in Medicaid LTSS" (see proposed 50-05-01, § 1.6 B). PASSAR provisions were never intended to enable

nursing facilities to become the default placement for individuals with I/DD. We are also not aware of any long-term care hospital in Rhode Island that provides the scope of benefits, which are required to be available in an ICF/I-DD.

The appropriate response to the lack of ICF/I-DD institutional settings is not to place individuals with I/DD and critical needs in an inappropriate institutional setting, but to develop sufficient community capacity to meet critical needs.

EOHHS Response: Modified this section to clarify the purpose of the provision: "The goal is two-fold: 1) Ensure care is available for those whose medical needs cannot otherwise be addressed; and 2) Limit the availability when any community-based alternative is available."

Section 1.8 HCBS Settings Requirements

It would be helpful to include the cited federal regulation, 42 C.F.R. § 441.700, in the list of authorities in § 1.2 A.2. That cited regulation contains the federal requirements for 1915(i) settings. Section 1.2 A.2., only specifically references the federal authority for 1915(c) settings, 42 C.F.R. §§
441.300 to 310. It's not clear whether the state intended any distinction by only citing to the 1915(i) provision in this section.

EOHHS Response: Done

While it is helpful to adopt the settings provisions of the federal rule by reference, these provisions are extensive and contain many important client rights regarding HCBS, including requirements that

> (i) The setting is integrated in and supports full access to the greater community, including opportunities to seek employment and work in competitive integrated settings, engage in community life, control personal resources, and receive services in the community, to the same degree of access as individuals not receiving Medicaid HCBS.
>
> (ii) The setting is selected by the individual from among setting options, including non disability specific settings and an option for a private unit in a residential setting. 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.
>
> (iii) Ensures an individual's rights of privacy, dignity and respect, and freedom from coercion and restraint.
>
> (iv) 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.

(v) Facilitates individual choice regarding services and supports, and who provides them.

(vi) In a provider-owned or controlled residential setting, in addition to the above qualities at paragraphs (a)(l)(i) through (v) of this section, the following additional conditions must be met:

(A) The unit or dwelling is a specific physical place that can be owned, rented, or occupied under a legally enforceable agreement by the individual receiving services, and the individual has, at a minimum, the same responsibilities and protections from eviction that tenants have under the landlord/tenant law of the state, county, city, or other designated entity. For settings in which landlord tenant laws do not apply, the State must ensure that a lease, residency agreement or other form of written agreement will be in place for each HCBS participant and that the document provides protections that address eviction processes and appeals comparable to those provided under the jurisdiction's landlord tenant law;

(B) Each individual has privacy in their sleeping or living unit:

(1) Units have entrance doors lockable by the individual, with only appropriate staff having keys to doors;
(2) Individuals sharing units have a choice of roommates in that setting; and
(3) Individuals have the freedom to furnish and decorate their sleeping or living units within the lease or other agreement.

(C) Individuals have the freedom and support to control their own schedules and activities, and have access to food at any time;
(D) Individuals are able to have visitors of their choosing at any time;
(E) The setting is physically accessible to the individual; and
(F) Any modification of the additional conditions, under paragraphs (a)(l)(vi) (A) through (D) of this section, must be supported by a specific assessed need and justified in the person-centered service plan. The following requirements must be documented in the person-centered service plan:

(1) Identify a specific and individualized assessed need.
(2) Document the positive interventions and supports used prior to any modifications to the person-centered service plan.
(3) Document less intrusive methods of meeting the need that have been tried but did not work.
(4) Include a clear description of the condition that is directly proportionate to the specific assessed need.
(5) Include regular collection and review of data to measure the ongoing effectiveness of the modification.
(6) Include established time limits for periodic reviews to determine if the modification is still necessary or can be terminated.
(7) Include the informed consent of the individual.

(8) Include an assurance that interventions and supports will cause no harm to the individual.

See 42 C.F.R § 441.710 (a)(l).

We ask that the state specifically include the full scope of the federal regulation requirements in this rule. It is unlikely that HCBS beneficiaries will ever learn of their rights, without the specific incorporation of these provisions in the regulation.

EOHHS Response: Done; included all of the language from the CFR noted above

Thank you for the opportunity to comment on this important rule. Please contact me if you have any questions regarding our comments.

Sincerely,

Anne M. Mulready
Supervising Attorney