



January 19, 2023

Allyson Raadmae
Administrator- Administrative Rules Unit
Department of Health and Human Services
105 Pleasant Street
Concord NH 03301

Via Email: Allyson.E.Raadmae@dhhs.nh.gov

Re: HeM 310, Rights of Persons Receiving Developmental Services or Acquired Brain Disorder Services in the Community

Dear Ms, Raadmae,

The Quality Council appreciates the changes that the Bureau of Developmental Services made to the proposed HeM 310 regulations in response to concerns raised by the Council in its letter to the Bureau in October 2020 prior to the development of proposed changes. While the Council was provided a brief opportunity review proposed changes to the HeM 310 regulations prior to the formal comment period, the Quality Council's initial recommendations were not incorporated, limiting the feedback that the Council could provide.

The Council has additional concerns with the proposed changes to the rule. Some of these were included in the initial comments and some are new, developed in response to specific proposed changes or additions.

In addition to the specific concerns addressed below, the Council believes that the rule must specify that information is provided to people with disabilities and families in plain language. In each mention of a notice, guide or other written documents, this must be included.

He-M 310.02 Definitions

Sexual abuse – The Council continues to be concerned about the definition of sexual abuse in this rule. People with developmental disabilities have the right to have consensual sexual relationships and we are concerned that the current definition which restricts any “contact or interaction of a sexual nature between an individual and an employee of or a consultant or volunteer for a provider agency” is too limiting. People with developmental disabilities regularly volunteer and work at provider agencies and have the right to consensual sexual relationships. We encourage the state to look toward other definitions of sexual abuse which typically rely on informed consent or hierarchical relationships.

Restraint – The Council is concerned that the definition of chemical restraint is too narrow and may create confusion, particularly in Section 2 (B). Involuntarily medicating someone to control their behavior or restrict their movement is a restraint, regardless of whether it is part of a behavior support plan or otherwise. Section b reads “Is not a standard treatment or dosage for the individual’s diagnosis.” The additional language does not seem necessary.

We want to be sure that chemical restraints are properly defined so that there is no confusion as to when chemical restraint is use.

Stephanie Patrick, Chair
Disability Rights Center - NH

Isadora Rodriguez-Legendre,
Vice Chair
*NH Council on
Developmental Disabilities*

Members

Ellen McCahon
Community Support Network, Inc

Rich Crocker
Area Agency Board Member

Carrie Duran
Family Support Council Member

Adrienne Evans
NH Council on ASD Member

Krysten Evans
*Advocates Building Lasting Equality
NH*

Jessica Gorton
Bureau of Developmental Services

Karen Hatch
Family Support Council Member

Emily Manire
Private Provider Network

Tammy Mills
People First of New Hampshire

Deb Opramolla
Family Support Council Member

Jim Piet
*NH Council on
Developmental Disabilities*

Liz Prior
Brain Injury Association of NH

Isadora Rodriguez-Legendre
*NH Council on
Developmental Disabilities*

Cathy Spinney
Area Agency Board Member

Mary St. Jacques
Institute on Disability

We believe that the Department must add definitions of “serious bodily harm” and “substantial property damage” as these are critical to the residency agreement section.

He-M 310.03 Notice of Rights of Individuals and Applicants

In the original comments on He-M 310, the Council recommended that Area Agencies must notify the individual with disabilities about his or her rights, even if a guardian has been appointment. It’s critical to empower the person with the disability by educating on that individual on their rights at every opportunity. It does not appear that this concern has been address. The Council suggests the following:

(4) Provider agencies shall advise individuals ~~or~~ and their guardians or representatives of individuals’ rights upon initial participation in any service, upon any change in provider agency or community residence, and at least once a year after initial participation.

He-M 310.04 Fundamental Rights

In the original comments, the Council recommended the following:

This section must make it clear that people with disability have same rights as people without disabilities. This section of the rule must clearly state that the individual with developmental disabilities retains all the rights guaranteed to people without disabilities. While this section specifies certain rights, it is not an exhaustive list. The person with the disability retains all rights unless specifically restricted as outlined below.

In addition, the section should clearly state that a person with a developmental disability has the right to direct his or her life, to make small and large decisions about activities, friends, home environment, etc.

“These rights are protected regardless of the place or residence of the person, type of service or support, ability to exercise these rights or choice to exercise these rights. It is the intent of this Chapter that these rights shall be applied in all provision of supports and services to persons with developmental disabilities.”

The rule should also clarify that area agencies, provider agencies and others are not allowed to informally restrict the rights of people with developmental disabilities. This would include any rights restrictions for safety reasons.

The rule must clearly outline the right of individuals with developmental disabilities to:

- Develop friendship of their choice
- Have romantic relationships, including LGBTQ relationships
- Engage in sexual activity with another person with informed consent from both individuals
- Have overnight visitors
- Text and call who they want and when they want
- Access to the internet

In response, the Department indicated that it does not want to include a list for fear that it would be understand as an exhaustive list rather than examples, but there is already a list of rights include. The Council believes that the rights above are critical and should be included in the rule so that they will be protected.

In addition, the right to vote is not guaranteed in the current rule; only the right to register to vote. This language should be changed to make it clear that individuals have the right to vote and service providers are responsible for assisting the individual to exercise this right by providing transportation or other supports.

He-M 310.05 Personal Rights

The Council recommended adding:

The right to communicate including access to technology or interpreter or other supports to facilitate communication.

This is not addressed in the draft changes. The section on communication addresses access to mail, telephone and visitors. It does not address access to communication supports, devices or interpreters to facilitate communication. While this may be addressed in other rules, the Council believes it is also critical to articulate it here.

Section (c) reads: *Individuals shall have the right to privacy.*

The Council recommended that the rule must clearly articulate that the right to privacy applies to both person and belongings and technology. The Bureau did not make this change. Once again, the Council believes that this change is important. Unless restricted in a behavior support plan, individuals with developmental disabilities deserve privacy of their cell phones, computer, tablet and other technology.

Section (f)(7) reads: No provider agency shall photograph, fingerprint, or record any individual by audio or visual equipment unless the individual, guardian, or representative has consented following an informed decision, nor allow any third party to photograph, fingerprint, or record any individual by audio or visual equipment unless the individual, guardian, or representative has consented following an informed decision, except if such monitoring or recording is part of a treatment program for a person committed in accordance with RSA 171-B;

The Council recommended the rule must clearly specify this restriction is not intended to restrict the right of a person with a disability to be or engage in activities in public or to communicate with peers. The Council believes that this restriction could be used to restrict an individual's ability to communicate with friends or family via the internet or take photos for private use and again recommends that this be clarified.

He-M 310.06 Service Rights.

Section (4)a specifies that the individual or representative has the right to a person-centered planning process that is directed by the individual or representative, if applicable. As noted above, you cannot have a person-centered planning process if the person with the disabilities is not participating in the creation of the plan and directing the process whenever possible. It is not sufficient to have on the representative participating or to have others directing the process. If the person with the disability is, because of the nature of his/her disability, is incapable of directing his or her plan, the legal guardian must do it.

This concern was not addressed by the Bureau. This language is not strong enough. The individual must lead their person-centered planning process. With the current language, the representative could lead the process and be in compliance with the law. In some cases, the service coordinator could develop the "person centered plan" without the individual or guardian involved in the process. That is not person-centered planning.

The Council believes that all individuals can participate in the person centered planning process even if their communication is limited or there are other barriers. If the individual is not involved, the state is not engaging in "person centered" planning.

The Council recommends that the state develop a definition and principles related to person centered planning so that it is clear that everyone involved in the DD system has a common definition. This definition should be incorporated in rules and law to ensure accountability.

Section 17

The Council remains concerned that the language around the use of restraints does not clearly specify that restraints should not regularly be used as part of a treatment plan. The concern below was not addressed.
Restraint and seclusion in response to behaviors should only be used when the individual presents a direct threat to himself or others, not when other treatments have not been effective. Restraint and seclusion are not treatments – they are an intervention in response to a dangerous situation.

We encourage the state to further detail expectations regarding the use of restraint in this rule, particularly in situations involving adults. This may include:

- When the patient is no longer a danger to themselves or others, the restraints should be removed immediately.
- Restraints should not cause harm or be used as punishment.

Section 18

The Department did not incorporate the Council's suggestion below and once again the Council believes that changes to this language are critical.

Section c, the language regarding maximizing the decision-making authority of the individual is weak. Provider agencies must maximize the decision-making authority of the individual. Any exceptions to this rule must be specifically justified and subject to appeal.

The Council suggests the following language:

(c) Provider agencies shall prioritize the decision-making authority of the individual.

He-M 310.07 Termination of Services.

The right to appeal, all reasons for the decision should be provided in plain language.

This recommendation was not addressed by the Bureau. The Council does not believe that there is an expectation that communication by in plain language and recommends that it be specified below to ensure individuals and families understand their rights.

- (1) Be in writing in plain language;

He-M 310.11 Behavior Change Program

The Council is concerned that representatives of individuals with disabilities are authorized to consent to the behavior change program without any expectation that the person with disabilities is involved in the development of the behavior change program. We suggest the following edit to Section C.

(c) The individual is provided the opportunity to be involved in the development of the behavior change program. ~~The A~~ individual, guardian, or representative shall agree to the terms of a behavior change program. In addition, we recommend that any program developed by provided to the individual with disabilities and their families in plain language.

He-M 310.10 Residency Agreement.

The Council recommends that the following be added:

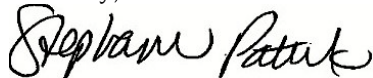
(b)(3)(c.) Implementing the resident's approved individual service agreement including any behavior support plan;

The Council recommends adding the following to (c) prior to Section 1. Before a termination request can be submitted due to behavior challenges, the provider shall assess the resident has a behavior support plan in place and whether the behavior was identified in the plan. If yes, the provider must assess whether the behavior support plan was being implemented. If yes, the provider shall assess in place, whether alternatives were considered. This information shall be included with the eviction notice.

In addition, the Council is concerned that there are significant exceptions to a person's ability to access the appeals process (e.g. if the basis for the termination is substantial damage to property). If the reason for termination falls into one of the exceptions, the individual must move out within 72 hours of receipt of the termination notice. Also, regardless of the reason for termination, unlike NH's landlord/tenant law, if the resident loses their initial hearing, there is no mechanism to have the decision reviewed by a higher court. Individuals are not provided with sufficient due process in the current draft of the rule.

Thank you for considering these comments. If you have any questions or want further information, please feel free to reach out to me or other members of the Rules and Regulations committee of the Council.

Sincerely,



Stephanie Patrick, Council Chair