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October 2020

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Initial Comments on He-M 310 Rule

The Quality Council appreciates the opportunity to comment on the He-M 310 rules, which protect the rights of all people with developmental disabilities across the state.

These comments were developed after numerous discussions at both the Quality Council's Rules and Regulations Committee and at the full Council. They are based on the current He-M 310 rule. The Council hopes to provide additional comments on draft revisions to the rule in the future.

Overview

In both law and statute, NH prioritizes the use of person-centered planning for all individuals served by the Developmental Disabilities Services System. The person with the disability is the core of person-centered planning. However, we are aware of few examples where the person-centered planning is regularly used to develop and update the individual service plans for individuals with developmental disabilities. In order to have a strong service system, the state must prioritize the true person-centered planning which empowers the individual with the disability to make decisions about their life. This must be emphasized throughout this document and the state must hold case managers and service providers accountable.

Relatedly, these rules must prioritize opportunities for the person with the disability to lead decisions about his or her care, even if he or she has a legal guardian. Under no circumstances should a person's "representative" be allowed to make decisions on his or her behalf without the input of the person with a disability.

He-M 310.01 Purpose

This section must clearly state that these rights apply to all people who have been determined eligible for services in the developmental disabilities system and acquired brain disorders in NH. This should include all people who are eligible for the DD or ABD waivers, family support services, and any other developmental disabilities services funded through Medicaid or state funds.

He-M 310.02 Definitions

The definitions of abuse and neglect must mirror the definitions in the statute. The current definition is too narrow.

Coercion is too narrowly defined. The definition should not be limited to actions by area agency staff. People with developmental disabilities have the right to be free from coercion by any service provider, staff or other.

The definition of sexual abuse is too narrow. We suggest the following definition: (c) "Sexual abuse" means contact or interaction of a sexual nature involving a vulnerable adult without his or her informed consent.

Restraint and seclusion must be defined. We suggest that the state relies on the definitions of restraint and seclusion in RSA 126U for guidance.

Provider agency definition must be updated to be clear that it includes area agencies, case management agencies and Medicaid-funded and other service providers.

He-M 310.03 Notice of Rights of Individuals and Applicants

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.

He-M 310.04 Fundamental Rights

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
- Vote. (The current rule only specifies the right to register to vote.)
- Text and call who they want and when they want
- Access to the internet
- Privacy related to technology

The rule must specify that rights can only be restricted through the formal service planning process, which includes the right to appeal any restriction, reconsideration of the restriction on a regular basis (every 3 months at maximum) and clear justification for the restriction. The individual with the disabilities must be provided the opportunity to participate in any discussions of rights restrictions. There must be a clear process to appeal rights restrictions.

In Section (b)(3), the process to restrict fundamental civil rights through a behavior change program is too vague. These are fundamental civil rights and the process to restrict them must be more detailed and thoughtful. It should include all the protections outlined above.

He-M 310.05 Personal Rights

The section on the use of restraint and seclusion must be expanded. The use of restraint or seclusion in response to behaviors must be a last resort.

The state should require regular reporting on the use of restraints by provider agencies.

Reporting should specify the reason that a restraint was used – safety, etc.

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

In addition, the state should consider the comments regarding the use of restraint and seclusion as provided by the Quality Council in the DD waiver comments process.

In section (f)(7), 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.

In section (c), the rule must clearly articulate that the right to privacy applies to both person and belongings and technology.

The process for complaints as outlined in this section must be more detailed and include timelines for responding to complaints and opportunities to appeal or file a grievance if the individual with a disability or their guardian disagrees with the outcome of the complaint process.

He-M 310.06 Service Rights

The language in part a: Individuals shall have the right to adequate and humane service and treatment must be strengthened. We can do more than provide adequate and humane services.

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.

As noted above, Section 17 needs significant revision regarding the use of restraint and seclusion. The types of restraint are not defined. 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 – it's an intervention in response to a dangerous situation.

The state needs clear guidelines on reporting and tracking restraints and requirements that providers actively reduce the use of restraint when it's used.

In Section A, 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.

He-M 310.08 Suspension of Services

We are concerned that this is beyond the scope of the law.

He-M 310.07 Termination of Services.

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

The Use of Behavior Intervention Plans or Intensive Treatment Program and Services to Restrict Rights

The restriction of the rights of a person with disabilities is a serious matter. Regardless of whether rights restrictions occur as part of a behavior plan, intensive treatment plan or other means, the person with the disabilities and his or her legal guardian must be involved in all steps of the process. This is necessary if the state is to hold true to its commitment to person centered planning.

The specifics of any behavior management program must be clearly explained in plain language that can be understood by everyone involved.

The state must define the role of the community of practice, human rights committee and other committees involved in the restriction of rights.

As outlined above, the state must clearly outline the individual's rights to appeal these decisions in formal and informal ways. The person with the disability and their guardian must be notified of their right to appeal at the time of the restriction and at least every three months as long as the restriction is in place.

Thank you for your consideration of these comments.

Regards,

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Chair

Area Agency Board Member Representative

Stephanie Patrick

Vice- Chair

Disability Rights Center Representative