DISABILITY RIGHTS MAINE

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Re: *Comments on* ***Regulations Governing Emergency Interventions and Behavioral Treatment for People with Intellectual Disabilities and/or Autism***

Dear Ms. Caswell:

Disability Rights Maine (DRM) is pleased to offer the following comments to the proposed revisions to the ***Regulations Governing Emergency Interventions and Behavioral Treatment for People with Intellectual Disabilities and/or Autism*** ("Behavior Regulations"), 14-197 C.M.R. Ch 5.

General Readability

DRM's first comment concerns the general readability and structure of the proposed changes. Though there remain similar principles to the current Behavior Regulations, the State appears to be recommending a complete repeal of the current text and replacement with wholly new terminology and format. While DRM does not oppose the complete rewriting of the Behavior Regulations, we urge that any revisions be clear and comprehensible to the community which seeks to use them. We have concerns that the proposed format is confusing, at times inconsistent, and overall not user-friendly.

The proposed Behavior Regulations appear to describe each level of intervention in four separate places with each segment having a slightly different focus. As it reads, §5.03 gives a short description of each intervention level; §5.04 and §5.05 give a more detailed description of each intervention level; §5.06 gives another short description of each intervention level with examples in a table format; and §5.08 restates the

documentary requirements for each intervention level. Re-describing each intervention level four separate times without using the exact same language allows for ambiguity and inconsistency. Furthermore, having to look in four separate places to gather information about a single intervention level makes it difficult to be assured that you have met each requirement.

For example:

- §5.02-32 defines Positive Support as "a support intended to increase opportunities for meaningful participation in community, making choices and learning skills to engage in Prosocial behavior."
- §5.03-1 describes Positive Support as a Level 1-2 intervention.
- §5.04-1(B)(1,4) describes additional requirements to provide opportunities and assistance to form and maintain friendships and participate in a broad range of activities. §5.04-3 describes further requirements for a Positive Support Plan including support for self-direction and building relationships.
- §5.05 describes "Behavior Management (Levels 3-5)" as plans that include restrictions of Rights or the use of Restraint (See §5.02-5). However, hidden in this section, is a statement that In-Home Stabilization which deprives the individual from access to the community for up to an hour is a Level 2 intervention. This conflicts with the prior sections which designate Level 1-2 as Positive Supports that increase community involvement. It also conflicts with this same section which states that restrictions of rights, such as access to the community, are Behavior Management Plans reviewed as Level 3-5 interventions.
- This conflicts again at §5.06 which describes Level 3 as "Programs which restrict a Person's Rights as enumerated in 34-B M.R.S. §5605", but then lists "Some programs which restrict a Person's activities or Rights for safety reasons" as a Level 2.

Setting aside the inconsistencies inherent in these sections, in order to fully understand Positive Supports, the reader must jump around this forty page document, including into sections which are titled something different.

Additionally, DRM has concerns that this document has not been thoroughly reviewed and that typing mistakes may have unintended consequences in interpretation. In particular, the liberal use of capitalizing versus not capitalizing specific words can change the dynamic of a sentence. For example, "Restraint" is a term which has been defined and has a specific meaning while "restraint" apparently

does not. This back and forth of sometimes using the defined Restraint and sometimes the undefined restraint could lead to misunderstandings. Similarly the State has also created capitalized terms throughout the document that are nowhere else defined, such as "Positive Behavior Modification Techniques". Also, the Department defined terms, such as "Noxious", which are then not used in any part of the implementing regulations. Finally, there remain typos and grammatical errors within the regulations which undermine the gravity of its tone.

DRM recommends that the State consider restructuring these regulations to increase readability and review this document to ensure that terminology that is used is the terminology which is intended.

Consistency in Emergency Terminology

This document describes instances in which a Planning Team is required to engage in a restraint and/or an intervention which violates the individual's rights. This is restated several times with slightly different ambiguous terminology each time, such as "danger", "harm" and "injury". DRM recommends using the same consistent and clear terminology each time in order to reduce confusion and unnecessary restraints and rights violations.

Towards this end, DRM recommends the following changes be made:

§5.02-15 Emergency: means a situation in which there is Imminent Risk of physical injury to the Person or others.
§5.03-2 If the Planning Team determines that Positive Supports alone are insufficient to prevent Imminent Risk of physical injury to the Person or others, the Planning Team must develop a Behavior Management Plan or follow Emergency Intervention Procedures within this rule.
§5.05 When a Person's Challenging Behavior presents an Imminent Risk of physical injury to the Person or others, the Planning Team must act to ensure the Person's safety.
§5.05-2(E) Restriction of Rights or the use of Restraints may be used only to keep a Person or others safe from Imminent Risk of physical injury to the Person or others…
§5.09-1 Emergencies occur when a Person's Challenging Behavior presents an Imminent Risk of physical injury to the Person or others.

§5.09-1(A) If necessary to protect the Person or others from Imminent Risk of physical injury to the Person or others, Restraint otherwise permitted in this regulation may be used on an Emergency basis.
§5.09-1(D) Emergency intervention may include temporary removal of personal property when there is an Imminent Risk of physical injury to the Person or others.

Personal Planning Team

As written, the proposed Behavior Regulations have created "A Personal Plan" which is different from that of the Person Centered Plan ("PCP"). This appears to be an oversight. DRM recommends making clear that the current rules regarding the PCP apply, including the person's right to participate in the development of the PCP, and make the following changes:

§5.02-29: Person Centered Plan: means a plan, as required by 34-B M.R.S. §5470-B ("Personal planning") that articulates and identifies the needs and desires of the Person and describes services which will be offered to achieve them. The Person Centered Plan may include a Positive Support Plan, a Behavior Management Plan, or other plans that describe how services will be delivered.
§5.02-31 Planning Team: means the Person and others who are responsible for developing the Person Centered Plan as required by 34-B M.R.S. §5470-B ("Personal planning").
§5.02- 22 IST: means an Individual Support Team consisting of the Person, other members of the Planning Team, and other professionals, family, or friends that the Planning Team determines would be supportive to the Person in a time of crisis…

Promoting Decision-Making as a Skill

DRM is in support of the changes to the Behavior Regulations which require the use of Positive Support as the first approach and least intrusive interventions. DRM is also in support of the use of Functional Assessments which promote opportunities and assistance in making choices and exercising personal autonomy. Too often, we see individuals adjudicated incapacitated when they simply need a small amount of support and guidance in developing decision-making skills.

Supported Decision-Making ("SDM") is a method of developing decision-making skills by relying on a team of supporters to assist the individual in collecting information, processing information, and coming to a reasoned decision. It provides a

trusted and formalized environment for individuals who are seeking assistance with decision-making while still promoting self-determination. SDM is flexible and can change with the needs of the individual to provide more opportunities for independence and autonomy.

DRM is the founding member of Maine's Supported Decision-Making Coalition which is a partnership of community leaders and individuals with disabilities providing training and outreach on Supported Decision-Making. The Coalition has already submitted recommendations to the Probate Advisory and Trust Law Commission that a Supported Decision-Making definition be included in the next legislative session to amend the Probate Code. DRM recommends including the same definition in the Behavior Regulations and including consideration of Supported Decision-Making as a Positive Support:

§5.02-49-A Supported Decision-Making means a process of supporting and accommodating a Person to enable the Person to make life decisions without impeding self-determination.
§5.04-1(B)(1) learn how to make choices, exercise personal autonomy, and develop decision-making skills using Supported Decision-Making.

Safety Devices

In our experience as a member of the 3-Person Committee and a resource for the community on Developmental Services, DRM has discovered state-wide inconsistencies in how each Committee and agency interprets Safety Devices. We believe this is due to the ambiguity in the current definition of Safety Device. The proposed Behavior Regulations use the same definition and DRM recommends that the State consider changes that would make the term clearer to the organizations attempting to implement them.

It is our understanding that the State's intent with Safety Devices is to regulate the use of devices which assist an individual with unintended movement.

For example: Using a seatbelt in a wheelchair to assist a person from falling out of the wheelchair during a seizure would be reviewed as a Safety Device. Using a seatbelt in a wheelchair to keep a person from standing up and eloping would be a Mechanical Restraint and reviewed as a Behavior Management Plan. The key difference being the

use of the same device to stop unintended movement in the former and intended movement in the latter.

DRM recommends that the State adopt changes to the definition of Safety Device which would make this distinction clearer:

5.02-45 Safety Device: means a device, limited to the person in question, whose effect is to reduce or inhibit the person's unintended movement in any way.

Therapeutic Devices

In contrast to Safety Devices, it is DRM's experience that the current regulations regarding Therapeutic Devices are clearer than that being proposed in the new Behavior Regulations.

The current regulations state: "These regulations are not intended to regulate the use of therapeutic adaptive equipment or therapeutic interventions in occupational or physical therapy". (14-197 C.M.R. Ch 5 §1(4))

The proposed regulations echo the same sentiment in the Applicability segment, however, then go further to expand the definition of Therapeutic Devices to include devices which are outside of that used in occupational or physical therapy. This distinction is critical in categorizing Therapeutic Devices and Safety Devices. DRM recommends making the following changes to make this distinction clearer:

§5.02-51 Therapeutic devices or interventions: means devices or interventions used in occupational or physical therapy which are designed to assist the Person in daily functioning as written in the Person Centered Plan. Therapeutic Devices or Interventions include, but are not limited to:…

Consistency in Consent Language

One of the critical differences between a Behavior Management Plan and a Positive Supports Plan is the person's consent to the intervention. Language describing this consent is again, slightly different each time it is restated. As previously stated, these slight differences could lead to misinterpretation.

For example, compare "…to which the Person does not object…" to "…to which the Person does not communicate an objection…" (proposed §5.05-3(E,F)). If the intention is to have the same effect in both, the wording should be the same. With the significant population of individuals who are still developing a communication system, leaving these discrepancies could allow for different treatment of individuals who have alternate communication styles.

DRM recommends making the following changes to keep the language consistent across the document:

§5.05-3(E) Therapeutic Devices or Interventions, or approved Safety Devices to which the Person consents and which are not intended as an intervention…
§5.05-3(F) Monitoring Devices intended to enhance independence, to which the Person consents and which are not intended as an intervention…
§5.06(Level 2) –Securing of incendiary material, clothes, shoes or sharps with documented safety issues or problematic misuse, to which the Person consents.
§5.06(Level 3) –An intervention to which the Person does not consent to.
-Buzzers/alarms/sensors or locks the Person is able to unlock on doors/windows, etc., if the Person or a member of the Planning Team does not consent or if a response to a Challenging Behavior.
-Electronic monitoring devices (video, ankle bracelet, etc.), when the Person or a member of the Planning Team does not consent or if a response to a Challenging Behavior.
§5.07 –Swaddling from which the Person can remove him or herself but to which the Person or other member of the Planning Team does not consent.

Length of Review

The current Behavior Regulations require that behavior plans that include rights restrictions or use of restraint be reviewed by the 3-Person Committee on a quarterly basis. The proposed Behavior Regulations default to an annual review. It is unclear why the State has chosen to extend the minimal time for review of the most intrusive elements of behavior management four-fold.

DRM is gravely concerned that increasing the minimum time for review will allow unnecessary and overly restrictive interventions to extend beyond the time needed. We strongly recommend keeping the current quarterly review and making the following changes to the proposed regulation:

§5.08-2(B)(3) The voting members of the Review Team have the discretion to determine duration of Behavior Management Plan approval to a maximum of three months. If less than three months, the duration of plan approval must be indicated in writing.

In-Home Stabilization

Currently, the act of systematically depriving an individual access to the community must have 3-Person Committee approval before implementation. These types of plans should be rare and only to prevent serious physical harm due to the extreme nature of the restriction. The proposed regulations would allow for systematic deprivation of community access for up to an hour even when there is no longer imminent risk of physical injury without any such review.

To be clear, encouraging and promoting community integration is, in many ways, the purpose of Developmental Services. For decades, individuals were segregated from the community in institutions, creating a stigma which the Supreme Court identified as discrimination in the famous Olmstead v. LC ruling. Home and Community Based Waiver Homes were created to allow individuals the opportunities to live and thrive in their own communities. Cultivating community access is arguably the central focus of service delivery[1]. I have attached a copy of the fundamentals of service delivery for reference.

That being said, it is no small thing to deprive someone access to the community for any length of time. Further, it cannot be said to be comparable to the Positive Support Plans implicit in Level 2 interventions. It is unnecessary to create this loophole which exists nowhere else in the regulations that allows a systematic rights violation without appropriate systematic review.

The serious nature of In-Home Stabilization Plans should be reflected in the review process. As with all other interventions, in emergency circumstances, In-Home Stabilization may be utilized to protect the person or others from imminent risk of physical harm. If it becomes necessary then to develop a plan for the systematic deprivation of community access, it should be reviewed as a Behavior Management Plan at Level 3-5 with all other rights restrictions.

[1] See 34-B M.R.S.A. §5610 "Service delivery"

To this end, DRM recommends that the State identify all In-Home Stabilization Plans as Level 3-5 interventions and make the following changes to clarify that In-Home Stabilization may be an emergency intervention:

5.02-20 In-Home Stabilization means a limited period of time for which a Person whose Challenging Behavior has placed that Person or others in Imminent Risk of physical harm may be denied access to the community.
5.05-3(D)(3) The proposed use of In-Home Stabilization for any planned length of time is a Level 3-5 intervention and must be derived from the Functional Assessment and incorporated into the Positive Support Plan.
5.05-3(D)(4) The proposed use of In-Home Stabilization for a period less than 24 hours, is a Level 3 intervention…
5.05-3(D)(5) In-Home Stabilization at Level 3 must not be applied cumulatively…
5.06(Level 2 Examples): ~~In-Home Stabilization for a maximum of one hour for safety and assessment.~~
5.06(Level 2 Required Documentation): Functional Assessment, Positive Support Plan, Transition Plan toward more naturally occurring reinforcers ~~or In-Home Stabilization Plan as indicated.~~
5.06(Level 3 Examples): In-Home Stabilization ~~for more than one hour for safety and assessment~~ not to exceed 24 hours.

Functional Assessment and Psychological Assessment

DRM greatly appreciates the State's choice to expand the licensure of qualified professionals to develop and oversee creation of Behavior Management Plans. In years past, it has been difficult for agencies and individuals to get the guidance they need due to the lack of Psychologists and Psychiatrists available to assist in the development of plans. We believe that the expansion to professionals, such as BCBAs and LCPCs, will allow for more clinicians dedicated to the growth of the individual.

DRM also appreciates the State's attention to defining and requiring Functional Assessments to educate the development of supports and intervention strategies. We support the need for Functional Assessments and the content to which it's prescribed. Our only concern is to identify appropriate professionals to conduct the Functional Assessment who will be available to assist with the development of a plan, should the Planning Team determine one is necessary.

To create a smoother transition between the Functional Assessment any potential plan, DRM recommends identifying the same professionals to create the Functional Assessment as would be the plan:

§5.04-2(D) The Functional Assessment must be 1. Completed by or under the supervision of a psychiatrist, a licensed psychologist or psychological examiner, a Licensed Clinical Social Worker, Licensed Clinical Professional Counselor, or a Board Certified Behavior Analyst.

We also recommend updating the Functional Assessment annually. The proposed regulations suggest updating the Functional Assessment every three years. This seems to undervalue the Functional Assessment as key to identifying environmental stressors and opportunities to promote independence in the person. Over the course of a year, people can change dramatically, especially after receiving targeted support for Challenging Behaviors. We believe it's important that the Functional Assessment be updated annually to reflect changes and potential improvement in the person's behavior by the following changes:

5.04-2(D)(4) updated annually, or more often as needed.

We similarly recommend that the Psychological Assessment be updated annually as opposed to the proposed three years for the same reasons. As the State has opened up the licensure of overseeing professionals, it corresponds that having some support from a Psychologist at least annually would provide for some psychological oversight and opportunity for consideration of interventions not yet explored.

5.05-4(B) … If Restraint or systematic restriction of Rights continues to be recommended in the Behavior Management Plan, the Psychological Assessment must be updated at least annually.

Reporting

There is currently a widely held misconception that prohibited elements of behavior management plans may be utilized as long as the use is reported to the State. Often, when plans do not receive approval from the 3-Person Committee, service providers will continue to use them and report their usage to the Enterprise Information System (EIS). This misunderstanding is commonly attributed to mandated reporting requirements which require such a use to be reported. However, much like the

mandated reporting of abuse, the abuser reporting the abuse does not absolve them of the act.

DRM urges the State to rectify this misconception in the proposed regulations and make the following changes:

§5.05-3(H) Any use of a prohibited intervention, restriction or use of Restraint in a manner inconsistent with this regulation must be reported as required in Departmental rule 14-197 Chapter 12, §6.03(C)…. Reporting does not absolve the reporter of liability for this type of violation of law and regulation.

Restraints (Assessment)

DRM agrees with and appreciates the State's decision to reduce the time for release during a restraint to fifteen minutes. DRM writes separately only to request that the State also maintain the current maximum of no longer than one continuous hour with 3-Person Committee approval by the following changes:

5.05-3(C) The use of Restraint without an attempt to release must not continue for longer than fifteen minutes, unless approved as a special circumstance by the Review Team up to a maximum of one hour…

DRM also recommends that the State maintain the current special assessment requirements when restraints have been identified as a potential intervention. The current regulations read:

Assessments must be utilized to establish the length of time the physical holding may be employed, up to the maximum allowed. Such assessment must be included as part of the planning process and must be discussed with the planning team as soon as is practicable after an episode. The assessment must specifically address issues of trauma (i.e., whether the physical holding of a person with a history of trauma would be more harmful than not doing so). 14-197 C.M.R. Ch 5 §4(3)(A)(2).

People with developmental disabilities experience sexual assault at a rate much higher than people without disabilities. Putting hands on a person with a history of trauma has the potential to escalate the situation. When restraint is identified as a potential intervention, it is critical to assess the least intrusive way to implement it. DRM

strongly recommends incorporating the current language into the requirements of Medical and Mental Health Assessment and Treatment.:

5.04-4(B) The Positive Support Plan must document how it incorporates factors related to trauma. Consideration must be given to the emotional and physical impact of the use of Restraint or other interventions. Assessments must be utilized to establish the length of time the physical holding may be employed, up to a maximum of one hour. The assessment must specifically address issues of trauma (i.e., whether the physical holding of a person with a history of trauma would be more harmful than not doing so).

Floor Restraints

DRM writes separately on restraints to bring its ongoing concerns about the use of floor restraints and restraints outside of current nationally certified physical intervention programs.

Though DRM commends the State for prohibiting the use of prone restraints, we remain concerned about the allowance of any floor restraints and specialized restraints which are not part of the service provider's nationally certified training. Because of the likelihood of asphyxiation, floor restraints remain the most dangerous types of restraints. Many training programs, like Mandt, have already removed all floor restraint training from their program citing to the investigative report titled *Deadly restraint*[2] which accounted for approximately 150 deaths per year during floor restraints.

Furthermore, the members of the 3-Person Committee are not in a position to judge whether a restraint designed by a service provider is more dangerous to the person than the Challenging Behavior. As a society, we rely on nationally recognized physical intervention programs to do the necessary research and studies to determine the safety of a hands-on technique. To allow service providers to amend those programs to include a new type of restraint invites risk of injury and liability. Moreover, should those nationally recognized organizations find that the individuals which they have certified to use their program are not applying it correctly, those individuals would likely be decertified.

[2] Weiss EM, et al., *Deadly restraint: a Hartford Courant investigative report,* Hartford Court 1998; October 11 – 15.

DRM recommends that the State prohibit any use of floor restraints, prohibit the use of restraints which are not part of a current, nationally certified physical intervention program, and remove proposed §5.09-2 "Specialized Intervention" as it relates to physical restraints.

Proposed §5.06 ("Table")

DRM has many concerns about the Table which describes and creates examples of Levels 1-5. The Table unnecessarily restates what has already been stated in prior sections and which will be again stated proposed §5.08. If anything, the Table only serves to provide conflicts and contradictions with the other sections.

The most serious of these concerns are within Level 2 which the Table describes as both "Non-coercive intervention with voluntary participation by the Person" and "Some programs which restrict a Person's activities or Rights for safety reasons." Proposed §5.05 explicitly states that all planned interventions which include restrictions of rights or the use of restraint are reviewed at Levels 3-5 as a Behavior Management Plan. This is consistent with the current review of Severely Intrusive Plans.

It is unclear then why the State has chosen to include multiple instances of rights violations within both its description and examples of Level 2 interventions. Interventions which systematically restrict the rights of individuals are a serious intrusion which should be monitored and reviewed by the 3-Person Committee.

We also have concerns about some of the undefined terminology used within the Table. For example: "Restriction of communication" within the Table is an example of a Level 3 intervention. Because "communication" is an undefined term, this could be interpreted to mean the removal of communication devices or other means by which an individual uses to communicate. Also, because the example is so broad, it could be interpreted to include restriction of communication with family members which is later expressly prohibited.

DRM recommends removing the Table entirely as it is simultaneously repetitive and inconsistent. If this is not possible, DRM minimally recommends removing the following rights violations from Level 2:

Description:
~~Some programs which restrict a Person's activities or Rights for safety reasons. Preservation of personal property and safety measures involving incendiary material or sharps.~~

Examples include, but not limited to:
~~In-Home Stabilization for a maximum of one hour for safety and assessment~~
Securing of incendiary material, clothes, shoes or sharps with documented safety issues or problematic misuse, to which the Person consents.
~~Restriction of food or liquid (with doctor's health or safety recommendation)~~

Confidentiality of Records

The proposed regulations seek to grant case manager's unrestricted access to the individual's record. While DRM understands and appreciates the intent behind making case managers responsible for monitoring behavior plans, confidentiality of records is an enumerated right of individuals receiving Developmental Services. In most cases, case managers will already have signed releases and the individual's consent to review their records. However, in the rare case where the individual does not consent to the release of these records, it would require Level 3-5 intervention to systematically violate their right to confidentiality.

DRM recommends removing "and the Person's record" from proposed §5.05-5(G)(1).

Thank you for your time, consideration, and this opportunity to comment on the proposed revisions to the Behavior Regulations.

Respectfully submitted,

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Developmental Services Advocacy