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March 12, 2014
Kelly Miller
Assistant Director
Office of Provider Standards and Review
Ohio Department of Developmental Disabilities
1810 Sullivant Ave
Columbus, OH 43222-1056

RE: Proposed Behavior Support Rule, OAC 5123:2-2-XX

Dear Ms. Miller,

Thank you for continuing to include Disability Rights Ohio (DRO) in the discussions regarding the proposed Behavior Support rule, Section 5123:2-2-XX of the Ohio Administrative Code. Ms. Miller, as you know, DRO has been a full participant at the table during the process to revise this rule. As the organization designated by the Governor under state and federal law to protect and advocate the rights of people with disabilities in the state of Ohio, one of our highest priorities is to reduce, if not eliminate, punitive and abusive use of restraint, seclusion, and other aversives in favor of positive behavior modification. The I/DD field has been a leader in this regard, and your department has been seen as the leader in state government in making positive changes regarding this issue.

Prior to the February 20th revisions, DRO believed that the Department was moving in a positive direction with respect to developing a rule that would encourage an environment that promotes safety, dignity, and respect for individuals with disabilities. Given that great progress had been made toward a rule that protected the interest of our common clients, people with developmental and intellectual disabilities, our staff was stunned by the conversations at the most recent workgroup meeting and the changes included in the most recent set of revisions. DRO strongly encourages the Department to develop a rule that is consistent with its own philosophy concerning respect for individual rights and dignity, implementation of positive culture, and trauma-informed care strategies. Essentially, in developing this proposed rule, the Department must follow current law, specifically, Ohio Revised Code 5123.62 and Ohio Administrative Code 5123:2-17-02.

Please note, DRO supports certain provisions of the proposed rule that reflect common sense best practices, including extending the rule to ICF providers; consolidating the behavior support plan within an individual's overall care plan; prohibiting the use of a manual restraint or mechanical restraint that has the potential to inhibit or restrict an individual's ability to breathe or that is medically contraindicated; and creating a more robust list of prohibited measures. However, DRO cannot support the other recently revised provisions in the proposed rule that are listed below.

1. Section 5123:2-2-XX(H)(4): Prohibited Measures: Disabling Assistive Technology. DRO strongly recommends including "disabling of an individual's assistive technology such as a wheelchair or

communication device” as a prohibited measure. Not prohibiting these measures will permit unnecessary restrictions to an individual’s rights. For example, DRO recently reviewed a behavior support plan that directed staff to turn off the power on an individual’s wheelchair for 24 hours if they viewed her behavior as aggressive. Without the ability to use her wheelchair the individual was in essence secluded and unable to engage in her environment. The action mentioned above is analogous to physically restraining a mobile individual for 24 hours, yet it would neither be prohibited nor restricted under the current version of the rule. Similarly, an increasing number of individuals are using assistive technology, including iPads and other tablets, to communicate. Removing the ability of the individual to communicate not only puts the individual at risk of harm, but violates the most fundamental of statutory, human, and constitutional rights. Disabling an individual’s assistive technology must be prohibited to protect the dignity of individuals.

2. Section 5123:2-2-XX(H)(12): Prohibited Measures: Rights Restrictions. DRO recommends restoring the language that prohibits restrictions of an individual’s rights as enumerated in 5123.62 of the Ohio Revised Code and 5123:2-17-02 of the Ohio Administrative Code. These rights include the right to timely access to appropriate medical treatment, the right to be free from emotional, psychological or physical abuse, the right to participate in the political process, and the right to be treated with courtesy and respect. DRO agrees with proposed Section 5123:2-2-XX(K)(2) that nothing in the rule should prevent any person from intervening in a crisis situation to ensure a person’s health or safety. However, *absent such an unforeseen crisis*, there is no reason why someone should experience a violation of their rights.

Additionally, it is a fundamental principle of administrative law that a rule cannot usurp a statute, so any attempt in this rule to override the Bill of Rights as established by the Ohio General Assembly would not only go against the Department’s stated philosophy of creating an environment of dignity, respect and trust, but would also face a challenge in the rule review process, as this proposed language would conflict with existing law about the rights of individuals with developmental disabilities.

3. Section 5123:2-2-XX(I)(1)(c): “Time-Out.” As discussed in the last meeting, the Department’s use of the term “time-out” is inappropriate, as the language is clearly referring to seclusion. The Department should acknowledge that its use of the term “time-out” in the proposed rule is actually “seclusion” and refer to it as such in the rule. In the Ohio Department of Education’s recently finalized rule regulating restraint and seclusion, the term “time-out” is defined as: a behavior intervention in which a student, for a limited and specified time, is separated from the class within the classroom or in a non-locked setting for the purpose of self-regulating and controlling his or her own behavior. *In a timeout, the student is not physically restrained or prevented from leaving the area by physical barriers.* See OAC 3301:15-35(A)(13).

DRO vehemently objects to and is disturbed by the Department’s willing inclusion of language that allows for seclusion of individuals with disabilities. Not only is seclusion a violation of an individual’s liberty rights, but seclusion interventions have been demonstrated to be a treatment failure and ineffective as a means of achieving positive behavior outcomes. Seclusion requires physical interaction by staff, which often leads to a higher level altercation and injury to both the person and staff member. These actions create trauma in the individual, leading to a vicious cycle that does not address the critical issues. The person and staff members are left at

higher risk of trauma and injury. The Department is well aware of more effective and safer methods for behavior support that are evidence based and data-driven.

4. Section 5123:2-2-XX(l)(2): Restrictive Measures that Require Prior Approval by the Human Rights Committee. DRO recommends changing the language that allows the use of restrictive measures in situations that pose direct and serious risk of emotional or psychological harm to self or others. These terms are vague and undefined, allowing for the use of restrictive techniques when there is no need for such measures.
5. Section 5123:2-2-XX(l)(2)(a): Chemical Restraints. DRO is dismayed that the Department supports the use of chemical restraints for individuals with developmental disabilities. Research has demonstrated that this practice is medically unsound. A peer-reviewed study examined individuals with intellectual disabilities who had demonstrated aggressive behavior. The study compared individuals with intellectual disabilities who were chemically restrained to a control group that was provided a placebo. At the end of the review period, the control group experienced the most reduction in instances of aggressive behavior¹. Additional reviews of literature have revealed that use of strong tranquilizers, anti-psychotics, and other drugs for off label purposes is ineffective^{2, 3} and exposes individuals to a multitude of adverse side-effects including weight gain, early onset of diabetes, blood disorders, and has an impact on brain development⁴.

The practice of chemical restraint is also legally unsound. There are problems with consent, as surrogates cannot adequately protect the interest of the individual in being subjected to unwanted and improper medication. DRO has seen numerous instances where some facility staff have abused use of these medications in order to keep "difficult" residents sedated; violating the rights and liberties of the individual.

DRO strongly recommends that chemical restraints be prohibited as a restrictive measure in order to protect the rights and well-being of individuals with developmental disabilities. The Department is aware of more effective and safer methods of behavior support that are evidence based and data-driven but do not impose health risks to individuals with disabilities. Medications, stimulants, tranquilizers and other psychotropic drugs should only be used when there is a valid medical order from a licensed physician for a documented condition as a prescribed course of treatment for that condition, and should be prohibited for all other purposes.

¹ Tyrer, Peter, et al. (2008) "Risperidone, haloperidol, and placebo in the treatment of aggressive challenging behavior in patients with intellectual disability: a randomized controlled trial". *The Lancet*. Vol 371. 19606. Pp 57-63.

² Deb, Shoumitro and William Fraser. (1994) "The Use of Psychotropic Medication in People with Learning Disability: Towards Rational Prescribing". *Human Psychopharmacology*. Vol. 9, pp 259-272

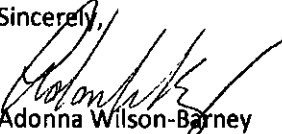
³ Deb, Shoumitro et al. (2008) "The effectiveness of mood stabilizers and antiepileptic medication for the management of behavior problems in adults with intellectual disability: a systemic review". *Journal of Intellectual Disability Research*. Vol 52. 1. 2 pp 107-113.

⁴ United States Department of Health and Human Services. National Institute of Mental Health. (2010) *Mental Health Medications*. NIH publication No. 12-3929. <http://www.nimh.nih.gov/health/publications/mental-health-medications/nimh-mental-health-medications.pdf>. Accessed 3/4/14.

6. Section 5123:2-2-XX(L): Human Rights Committee. DRO is concerned that the rule allows for a human rights committee to be comprised of only two members, and does not require that there be representation of individuals with developmental disabilities. In order for the human rights committee to be truly fair and effective, individuals with disabilities must be represented and participate on the committee. DRO recommends language that requires a minimum of six individuals, two of whom are individuals with disabilities, two are family members, and two are county board members or providers.
7. Section 5123:2-2-XX(I): Restrictive Measures that Require Prior Approval. DRO strongly recommends that there be reporting and notification requirements when restrictive measures are used. DRO recommends that an individual's family member (with consent of the individual), guardian, or authorized representative be informed immediately when a restrictive measure is used. The notification should include what actions by the individual posed an imminent risk, any attempts to deescalate the situation or avoid the use of the restrictive measure, the type of restrictive measure that was used, how long the restrictive measure was used, and a plan of action that describes how they will prevent future uses of restrictive measures.
8. Section 5123:2-2-XX(P): Waiver Authority. DRO questions the need for this provision within the rule. If it is included, it should be used sparingly, for documented cause, should apply only to limited parts of the rule, and for time limited periods only.

Thank you for your time and consideration on this important proposed rule. I look forward to working with the Department throughout the rule development process. Please feel free to contact me at extension 136 should you have any questions or concerns.

Sincerely,



Adonna Wilson-Barney
Senior Advocate

c: John Martin, Director