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October 5, 2018

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Department of Behavioral Health, Developmental Disabilities
and Hospitals
BHDDH Office of Legal Counsel
Hazard Building,
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Cranston, RI 02920

Re: Comments on Proposed Rules 212-RICR-10-05-01, Rules and Regulations for Developmental Disability Organizations, and Proposed Repeal of the Rules and Regulations Relating to the Definition of Developmentally Disabled Adult.

Dear Attorney Theriault:

On behalf of the Rhode Island Disability Law Center, Inc. (RIDLC), we are submitting comments on the above-referenced two rules. RIDLC is the non-profit law office designated as the state's Protection and Advocacy (P&A) agency for individuals with disabilities within Rhode Island. As the state's P&A we advocate for individuals with developmental disabilities to help assert their legal and human rights, as well as investigate allegations of abuse and/or neglect. We have a strong interest in assuring that Department's rules promote individual autonomy and rights, while ensuring that individuals'service needs are met. Our comments on the two rules follow. Please note they are in the order of the rules, and not necessarily in the order of importance.

212-RICR-10-05-01, Rules and Regulations for Developmental Disability Organizations

§ 1.1 B. Rather than using "least restrictive environment," it would be more appropriate to use the language of the Americans with Disabilities Act(ADA) "most integrated setting," which is applicable to state government programs and services.

§1.2 A.1.a.(2). Incidents of physical abuse between to individuals with development disabilities may result from staff neglect and thus should be reported to the Office of Quality Assurance in all cases.

§1.2 A. 3. The additional qualifier "Whenever possible an advocate should be selected by the person with a disability" as found within RI Gen. Laws § 40.1-26-2(1) should be added to the definition of advocate.

§1.2 A. 29. Missing from the description of the role of the human rights committee is the receipt and review of grievance reports. This provision should be added. *See* R.I. Gen. Laws § 40.1-26-4(e).

§1.2 A.29.b. This paragraph references the role of the human rights committee regarding "[r]eviewing …individuals' plans designed to modify behavior which utilize aversive techniques…." While this mirrors the language in R.I. Gen. Laws § 40.1-26-4(c) regarding the role HRC; it should also reflect that R.I. Gen. Laws § 40.1-26-4.1 appears to prohibits the use of all aversive interventions for individuals with developmental disabilities. This would apply to all other sections that reference aversive techniques as well such as §1.12 A. 2.

§1.2 A.32.b. This paragraph should be amended to add that the person should be given information about expected prognosis with the proposed treatment, expected prognosis without the proposed treatment, and any less invasive alternatives to the proposed treatment.

§1.2 A. 49. It does not make sense for BHDDH to only license group homes that have SSI residents living within them. Residents may include individuals who do not have SSI income, but have other sources of income including Social Security Disability Insurance (SSDI) and earnings. The reference to SSI should be removed.

§ 1.3. 1 B. 1. Legal representative is not defined, so it's not clear what kind of legal representative the DDO is prohibited from becoming. Representative Payees are often considered "legal representatives" for the purpose of managing SSI or SSDI benefits. In the following section 1.3.1 C, the Department recognizes that a DDO may be a representative payee. It would be helpful to clarify what definition BHDDH intends for "legal representative."

§ 1.5. This section has some inconsistencies with the statute, R.I. Gen. Laws § 40.1-26-5. The statute requires that the grievance be filed with the director of the agency. It may be permissible for BHDDH to expand the entities who can accept a grievance (subsection D says grievances can be filed with the Department or with the chair of human rights committee). These entities would then have to make sure a copy went to the agency director, not the chair of the human rights committee. Additionally the statute requires that the agency director issue a written decision within five (5) business days of the receipt of the grievance, not ten (10) as authorized the proposed rule. The Department does not have the authority to extend this timeframe.

§ 1.6. The statute also says that the a grievant who is not satisfied with the agency's decision has "the right to appeal that decision under regulations promulgated by the Department of Behavioral Healthcare, Developmental Disabilities and Hospitals" and to have that matter treated as a "contested case" under RI Gen. Laws § 42-35-9. We do not believe this statutory requirement is

met by providing access to the EOHHS appeals process under 210- RICR-10-05-02. It is particularly important for BHDDH to have notice of, and an opportunity to resolve grievances, which it will not necessarily have if the EOHHS appeals process is followed.

§ 1.7. This proposed termination of service procedure is a departure from the existing regulations, in that it eliminates the Department's role in approving any transition plan that is developed by the agency that is terminating service. We believe the Department's oversight of this planning should continue.

We also believe this section should advise participants of their right to maintain existing services pending a fair hearing pursuant to Medicaid law, and as described in the EOHHS appeals process under 210- RICR-10-05-02, § 2.2.2.

§1.10.1. This section is entitled Health Education but does not make reference to any health education other than sex education. It should be entitled Sex Education.

§1.10.4.E.2. This section references an abuse/neglect registry as part of respite care service providers' background checks. Does the state keep such a registry?

§ 1.11.2. This section about medical care does not make any references to medical specialists such as cardiologists, endocrinologists, neurologists, psychiatrists, rheumatologists, ophthalmologists…that individuals may be followed by or referred to for evaluation and treatment. Perhaps insert as new paragraph B. that DDOs shall ensure that individuals have access to specialty physicians such as but not limited to cardiologists, endocrinologists, neurologists, psychiatrists, rheumatologists, and ophthalmologists as recommended for monitoring, evaluating and treating, and move the other paragraphs down.

§1.12 A. 2.b.(1) and (2). These sections state that an individual can only be determined "not competent" by a court. First, it should state that an individual is presumed competent. Second, it should use determined to lack capacity to make a particular decision or decisions. Since 1992, the Rhode Island Guardianship statute has used this language. See RI Gen. Laws §§33-15-1 et seq. Also since 1992, while it does not always happen, all guardianships are supposed to be limited to those decisions an individual lacks the capacity to make. Third, it should also note that guardians are not authorized to make every decision; for example, a guardian does not have the authority to sign the individual in to a psychiatric facility over their objection under the mental health law. It is our position that certain other controversial decisions should not be authorized without due process regarding the particular decision, such as the proposed use of sterilization or electro-convulsive therapy. Fourth, some individuals under legal guardianship may have the capacity to execute a durable power of attorney for health care. State law does place limits on who may be appointed as an agent pursuant to a durable power of attorney for health care; the paragraph should reflect the law. See RI Gen. Laws §23-4.10-2.

Lastly, we are extremely concerned about the removal of any Clients'Rights Information from this proposed rule. The "Summary of Proposed Action on the Rule" para. 24 indicates that Participants rights was moved in its entirety to the BHDDH General Licensing regulations, 212-RICR-10-00-01. Section 1.26 of that proposed rule merely incorporates statutory rights by reference (including rights specific to individuals with developmental disabilities, under RI Gen. Laws 40.1-26-3).

It is not clear why the Department would choose to publicize client rights information in such an obscure and non-transparent manner. It would seem critical especially for individuals with I/DD to have easy access to rights information, rather than be expected to navigate through all the multiple steps and cross-references needed to find rights information. Even more puzzling is the fact that the Department chose to retain Client Rights information within its proposed rule on Behavioral Health Organizations. See § 1.5 of proposed 212-RICR-10-10-1. We urge the Department to add back clients' rights information to this rule on developmental disability services.

Proposed Repeal of the Rules and Regulations Relating to the Definition of Developmentally Disabled Adult

We could find no explanation of the Department's rationale for repeal of this rule. Our recollection is that this rule was promulgated in response to RIDLC's allegations within a lawsuit that the Department's decision-making process for determining eligibility under state law for developmental disability services was inconsistent and arbitrary and violated due process. By eliminating the publication of any standards for determining eligibility, the Department subjects itself to similar allegations in the future.

Sincerely,

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