

March 23, 2012

Susan Del Pesco, Director
Department of Health and Social Services
Division of Long Term Care Residents Protection
3 Mill Road, Suite 3308
Wilmington, DE 18806

RE: DLTCRP Proposed Intensive Behavioral Support and Educational Residences (IBSER) Regulation [15 DE Reg. 1264 (3.1.12)]

Dear Ms. Del Pesco:

The Governor's Advisory Council for Exceptional Citizens (GACEC) shared forty-three comments on an earlier version of this proposed regulation published last Fall [15 DE Reg. 600 (11/1/11)]. Rather than adopting a final regulation, the Division of Long-term Care Residents Protection (DLTCRP) is issuing a revised set of proposed regulations. The GACEC would like to share the following thirty-two observations on the revised set of proposed regulations.

1. The revised regulation incorporates many of the recommendations made by the GACEC, including the following: inclusion of "purposes" and "authority" sections (§§1.0 and 2.0); improving the definition of "legal representative" (§3.0); clarifying the application of the regulation to day program participants (§3.0); including an accessibility reference in §6.1.2; authorizing non-glass shower doors (§6.5.3); disallowing children sharing rooms with adults (§6.6.15); requiring notice near phones of the DLTCRP telephone number (§6.12.3); requiring carbon monoxide detectors (§8.3); requiring certain information be included in agency website (§10.2); adding a general 5 year retention of records standard (§11.1.3); requiring maintenance of fire and comprehensive general liability insurance (§12.0); eliminating "criminal justice" as a relevant background degree (§13.2.4); requiring training in safe and effective behavior management techniques (§14.3.3); requiring monthly HRC meetings (§17.1.1.3); and requiring retention of incident reports for four years (§24.2).

2. The title to §1.0 is "Purpose Definition". This is unclear. Moreover, there is still no "operational" language reciting that the standards apply to Intensive Behavioral Support and Educational Residences (IBSERs) and no "purposes" language despite the title. Compare the neighborhood home regulation, 15 DE Reg. 968 (January 1, 2012), §1.0:

The purpose of these regulations is to provide a sequence of expectations for services rendered by the Neighborhood Home provider and a system for Neighborhood Home providers to be accountable to the Division of Long Term Care Residents Protection

(DLTCRP) and the Division of Developmental Disabilities Services (DDDS).

[emphasis supplied] There is no analog in the IBSER regulation.

The GACEC recommends changing the heading to “Purpose” (deleting “Definition”) and adding the following sentence:

The purpose of these regulations is to provide a set of expectations for the operation of IBSEs and ensure accountability to the Division of Long Term Care Residents Protection (DLTCRP).

3. The definition of “mechanical restraint” apparently seeks to exempt equipment and devices with a medical basis (e.g. prone stander; bed siderails). However, the definition would literally authorize a non-medical, undefined mental health “therapist” to authorize any form of mechanical restraint to prevent self-injurious behaviors or SIBS. At a minimum, the reference should be changed to occupational or physical therapist.

4. The definition of “mechanical restraint” is otherwise problematic. Literally, any equipment used to deter SIBS is per se not a “restraint”. As a consequence, it would be exempt from inclusion in the specialized behavior support (SBS) plan (§20.2.2), review by the Behavior Management Committee (§§18.2 and 18.3), and review by the HRC (§§17.1.2 and 18.3). Thus, use of a helmet, mittens, or other Assistive Technology would be exempt from many procedural safeguards. This is not “best practice” and is inconsistent with DDDS policy (e.g. DDDS HRCs review use of helmets, mittens, and AT used for Self Injurious Behavior (SIBS) prevention).

5. In the definition of “physical restraint, it would be more logical to transfer the second sentence (barring certain forms of restraint) to §20.11 (containing list of 12 forms of prohibited restraint). Moreover, the reference to “free movement of the resident’s diaphragm or chest that restricts the airway” could be improved. Some states have focused on pressure on certain body parts as more instructive. Consider the following prohibition: “Restraint that interferes with the resident’s ability to breath or places weight or pressure on the resident’s throat, neck, lungs, chest, sternum, diaphragm, or back.”

6. There is a definition of “seclusion” but no regulation which addresses it. The November version of the regulation explicitly banned the use of seclusion in section 19.8.12. The Bill of Rights Act explicitly bars “involuntary seclusion” without exception [Title 16 Del.C. §1121(24)]. Therefore, the IBSER regulation must conform to the statute and the ban should be reinstated. Parenthetically, this is consistent with “best practice”. See Section 4 of S. 2020 introduced by Senator Harkins in December, 2011.

7. The definition of “Specialized Behavior Support Plan” is flawed. Literally, the plan is expected to include the restraint of a resident to protect the resident from others. Why would an agency use a restraint on an individual to prevent his/her victimization from others? Immobilizing the victim will only exacerbate the victimization.

8. In §5.5, the comma should be deleted.

9. The DLTCRP Neighborhood Home regulation imposes the following obligation:

4.2.7.2. The Policy Memorandum 46 (PM 46) policy for reporting abuse, assault, attempted suicide, mistreatment, neglect, financial exploitation and significant injury is followed.

15 DE Admin Code 968, §4.2.7.2 (January 1, 2012) (proposed). There is no analog in the IBSER regulation. The DLTCRP could consider inserting a similar recital as a new §5.10 or within §19.0.

10. In the commentary on the November version of the regulations, the Councils provided a multi-pronged critique of allowing a 16-bed facility. See, e.g., Par. 11 of the earlier comments of the GACEC, which are attached for your reference. The new regulation reflects a compromise in which 16-bed facilities are “grandfathered” and new facilities must have no more than 10 residents. Segregated residential settings with 10 or 16 individuals per unit are not consistent with best practice and may violate the Americans with Disabilities Act (ADA). Consider the DHSS-DOJ DPC Settlement Agreement signed in July, 2011. That Agreement, which is based on the DOJ’s interpretation of the ADA, does not contemplate large congregate living arrangements. Rather it restricts supported housing to two individuals per unit with a separate bedroom for each resident (§II.E.). A 16-bed facility in which adult residents are “squeezed” into tiny rooms (§6.6.1) with age-inappropriate bunk beds (§6.6.11) smacks of “warehousing”.

11. Section 6.2.2 should be amended to include a reference to “legal representative” since the list of authorized visitors entitled to meet in private is literally limited to four types. Compare Title 16 Del.C. §1121(11)

12. The Councils had previously objected to 200 square foot bedrooms with four individuals. See attached GACEC letter, Par. 14. New §6.6 contains a “grandfather” provision for bedroom occupancy. New facilities will require 80 square feet for single occupancy and 130 square feet for double occupancy. This is still less floor space than required in group homes for double occupancy for persons with mental illness. See 16 DE Admin Code 3305, §12.2.2 (requiring 160 square feet for double occupancy). Likewise, the latter regulation disallows counting areas with lockers, wardrobes, vestibules, and alcoves. This limit is absent from the IBSER regulation. At a minimum, double occupancy standards should be no less than mental health group home standards (160 square feet exclusive of closets, lockers, wardrobes, vestibules and alcoves).

13. In §6.6.11, the authorization for adults to sleep in bunk beds is not age-appropriate.

14. In §6.5 or 6.7, the Division may wish to consult a dental expert. It may be appropriate to require a facility using well water to offer a fluoride rinse to some residents. Medicaid does not cover adult dental care and DDDS struggles with dental remediation which could be reduced through access to fluoride rinse in the absence of fluoridated water.

15. The DLTCRP Neighborhood Home regulations [15 DE Reg. 968, §4.6.6.7 (January 1, 2012) (proposed)] contain the following requirement: “(n)on-perishable food and capacity to store 1

gallon of potable water per person per day for at least a 72-hour period is present”. The Division could consider adding a similar water storage capacity standard to §7.10.

16. In §13.2.3.1, a direct care worker is required to be 21 years of age and possess a high school diploma. The Division may wish to consider the merits of substituting “18” for “21”. The change would allow college students (e.g. in human service fields such as psychology) to work part-time as direct care workers. Alternatively, the regulation could allow individuals to be employed as direct care workers between the ages of 18-20 only if they are college students in a human services field (defined in §§13.2.1.1, 13.2.4.1 and 13.2.5.1).

17. In §14.5.2, substitute “resident” for “patient”.

18. Section 17.0 merits reconsideration. The only agency to which the IBSER regulation applies presented its first of many cases to the DDDS Human Rights Committee (HRC) on February 29, 2012. The DDDS HRC does not include individuals with the qualifications listed in §17.1.1.2, including a licensed physician and licensed psychologist. On the other hand, the standards for the “internal” HRC are weak in the context of impartiality. DDDS amended its policy many years ago to require 100% membership by individuals external to DDDS. The IBSER regulation only requires a majority of external members and the “spirit” of this regulation may be undermined in practice by including a recent agency retiree as an “external” HRC member.

19. Section 18.1 refers to “the licensee’s clinical director”. There is no requirement that an agency have a “clinical director” and no definition of a “clinical director” in §13.0.

20. Although §20.7 contains a reference to data collection, it would be preferable to explicitly include a reference to presentation of data to the Behavior Management Committee (BMC) in §18.2.1.

21. In §19.2, it would be preferable to include a reference to “contractor”. The only agency currently subject to the IBSER regulation uses physician contractors.

22. Section 20.2.1 may be the most problematic standard in the regulations. It authorizes restraint based on the following benchmark:

The resident is exhibiting a problem behavior that is so severe that it poses a risk to the safety and wellbeing of the resident or others;

Authorizing the use of restraint based on the “safety and wellbeing” of the resident or others is vague and an invitation to overuse of restraint. If restraint is authorized by government, it is commonly restricted to an imminent risk of serious bodily injury to self or others. See, e.g., attached S.2020, Section 4. The concept of “imminency” is incorporated into §20.8.3 as material to termination of restraint but is absent from the standards for initiation of restraint. Moreover, if government does authorize the use of restraint, it is also common to ban the use of mechanical restraint. See S. 2020, Section 4. Use of strait jackets, wrap mats, rope and tape to restrict access to body parts is viewed as inherently intrusive. Cf. the attached February 12, 2012 News Journal article describing prosecution of a teacher for false imprisonment and endangering the

welfare of a child based on tying the hands of a child with autism.

23. Section 20.3 refers to an undefined “SPTeam” which includes an undefined “properly credentialed professional”. It would be preferable to add “, licensed” after “credentialed” since agencies may otherwise use marginally qualified “behavior analysts” without an advanced degree to develop an SBS Plan.

24. The only agency to which the regulation will apply uses video cameras throughout its buildings. It would be preferable to amend §20.9 to require maintenance of any recorded episode of restraint. Such a recording would be of diagnostic and training value for the SPTeam, HRC, and administration. It may also be of value to the DLTCRP.

25. Section 20.9.1 contemplates “clinical review and approval for interventions longer than 15 minutes”. Who has the authority to issue the approval? Is a “direct care worker” with high school diploma (§13.2.3.1) a “clinician” who can approve extended restraint? Within the DDDS HRC, it is common to require approval by the agency’s clinical director or alternate. The IBSER regulation refers to a clinical director in §18.1 but does not require a clinical director (§13.0) and does not define a “clinical director”.

26 Section 20.9.2 requires “(a)pproval by a clinician within one business day of an intervention when a restraint utilization event is less than 15 minutes.” There are two concerns with this provision. First, there is no definition of a “clinician”. Second, it is somewhat odd to retroactively “approve” an intervention a day after it was employed unless the intent is to prompt review to deter misuse.

27. It would be preferable to include a new §20.11.13 to read as follows: “Consistent with 34 C.F.R. §§300.2 (c) and 300.146, use of restraint or forms of aversive techniques on adult IDEA-funded residential or students which violate applicable law or regulation of the public IDEA funding agency.

28. Since the regulation covers adults, the reference to “parents” in §22.6 is inappropriate. It would be preferable to refer to the consent of “the resident or legal representative” rather than “parents or legal guardian”.

29. Although there is a short “universal precautions” section (§23.0), there is no section which addresses laundry. In practice, the facility could commingle the laundry of 16 individuals in cold water and spread disease. Compare 16 DE Admin Code 3201, §7.6.

30. Section 24.1 could be improved by including the following after “witnesses;”: “the existence of any video record of the incident”.

31. In §§24.4.2 and 24.4.4, it is inconsistent to require reporting of resident - resident emotional abuse while exempting reporting of resident - resident physical abuse in the absence of injury.

32. Section 24.4.11 only requires reporting of medication errors if the error causes discomfort, jeopardizes health/safety, or requires 48 hours of monitoring. The exceptions provide subjective

bases to withhold reporting to the Division.

Thank you in advance for your time and consideration of our observations. Please feel free to contact me or Wendy Strauss should you have questions.

Sincerely,

Robert D. Overmiller
Past Chairperson

RDO:kpc

CC: The Honorable Rita Landgraf, Delaware Health and Social Services
Jane Gallivan, Division of Developmental Disabilities Services
Kevin A. Huckshorn, RN, MSN, CAP, Division of Substance Abuse and Mental Health