

Delaware Developmental Disabilities Council

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November 21, 2011

Susan Del Pesco, Director
Department of Health & Social Services
Division of Long Term Care Residents Protection
3 Mill Rd., Suite 308
Wilmington, DE 19806

RE: DLTCRP Proposed IBSER Regulation [15 DE Reg. 600 (November 1, 2011)]

Dear Ms. Del Pesco,

The Developmental Disabilities Council (DDC) understands that the Division of Long Term Care Residents Protection (LTCRP) proposes to adopt a new regulation covering “Intensive Behavioral Support and Educational Residences”. The acronym is “IBSER” at 600. We thank you for this opportunity to comment on this new regulation.

We offer the following observations and recommendations.

1. In §1.0, the definition of “Intensive Behavioral Support and Educational Residence (IBSER)” is extremely problematic.

First, it literally recites that the IBSER regulations apply to “individuals” irrespective of their residence. The regulation should recite that it applies to covered facilities. This observation underscores a significant omission in the regulation, i.e., it omits “purpose” and “authority and applicability” sections altogether. Compare regulations covering assisted living and group homes, 16 DE Admin Code Parts 3225 and 3305. Conceptually, there is no recital that the regulation applies to defined IBSEs which shall conform their operations to the regulation. Such a recital should not appear in a definition (e.g. last sentence in §1.0) but in an “authority and applicability” section and it should apply to facilities, not individuals.

Second, it contains the following reference: “dual diagnoses of severe mental or emotional disturbance and who have specialized behavioral needs”. This makes no sense. Having “specialized behavioral needs” is not a “diagnosis”. An alternate interpretation is that the “specialized behavioral needs” reference applies to autism, developmental disabilities, and mental/emotional “disturbances” in which case the reference to “dual diagnoses” makes no sense.



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2. The references to “specialized behavior support plan (SBS Plan)” and “comprehensive behavior support plan” are confusing. The definition of SBS Plan indicates that the comprehensive behavior support plan is an optional supplement to the SBS. There is no or conflicting guidance on when a “comprehensive” plan must be in effect. For example, §19.2.2 indicates that restraint can only be part of a “comprehensive” plan. Other sections contemplate restraint being incorporated in the “specialized” plan. See, e.g., §2.0, definition of SBS Plan, second sentence; and §16.2.2.2.3. Multiple sections appear to authorize “comprehensive” plans with or without a restraint component. See, e.g., §§19.3, 19.4, and 19.5. The differences between the plans, and guidance on when each type of plan is required, should be clarified. Alternatively, it would be much simpler to have a single plan for everyone.

3. In §2.0, definition of “chemical restraint”, the reference to “not part of the individual’s usual medication regimen” could result in a loophole. In effect, if a physician prescribes a psychotropic medication as a “PRN”, this could be construed as part of the individual’s “usual medication regimen”. Alternatively, the prescription of a daily “tranquilizer” would be part of the “usual medication regimen”.

4. In §2.0, definition of “funding agency”, delete “is”.

5. Section 2.0 includes a definition of “legal representative” which merits reconsideration.

First, it is “odd” to include “payor source” as a “legal representative”. It creates problems with use of the term in the context of consent. A “payor source” has no consent authority.

Second, the term is seldom used in the regulation. See, e.g., §19.1. Instead, there are many inconsistent references to guardians, surrogates, family members, and responsible parties. See, e.g., §§2.0, definition of SBS Plan; §16.4.1; §19.4.2; and §24.1.2. It would be preferable to use the uniform term “legal representative” throughout the regulation.

6. In §2.0, the definition of “resident” is “the individual residing in the IBSER and subject to IBSER regulation.” It is unclear if adult “day students” are covered by the regulation, in whole or in part. For example, could an IBSER impose otherwise barred prone restraint, seated basket holds, chemical restraint, and seclusion on day students?

7. Section 2.0, definition of “restraint”, contains a final sentence barring 2 forms of restraint. It is “odd” to refer to 2 forms of barred restraint in the definition section when §19.8 contains a lengthy list of prohibited forms of restraint.

8. In §2.0, definition of SBS Plan, consider substituting “resident or legal representative” for “resident, his or her guardian or surrogate”. See discussion in Par. 5.

9. In §3.3.2, consider deletion of “must”.

10. Section 5.0 contains some safety-related accessibility features (e.g. handrails in showers; bright lighting; barriers to deter falls in elevated areas). Since there is positive correlation between cognitive developmental disabilities and mobility impairments, it would be preferable to also promote the physical accessibility of facilities. In §5.1.2, the word “accessibility” could be inserted between the word “education” and words “and construction”. In other contexts (e.g. furniture), the regulation envisions furnishings compatible with the “capabilities of the residents”. See §§5.1.7.2 and 5.1.8.1.

11. Section 5.1.7.1 allows up to 16 residents per residence. This is not consistent with “best practice”. These are not “group homes”. In contrast, neighborhood homes have 5 or fewer residents [16 DE Admin Code Part 3310, §1.0] and group homes for persons with mental illness have 10 or fewer residents [16 DE Admin Code Part 3305, §2.0]. State law [Title 9 Del.C. §2612] requires New Castle County to treat residential facilities for persons with disabilities with up to 10 residents as single family residences. As a consequence, almost all supervised residential facilities stay under the “10 resident” cap to avoid zoning problems. There is some “tension” between the “Olmstead” decision and placement of individuals with disabilities in such large congregate living arrangements. The DLTCRP may wish to consider prospects for reducing the size of such facilities over time (e.g. disallowing new licensed facilities from opening with more than 4-5 persons per residence). Existing facilities could be “grandfathered” on a temporary or long-term basis. The most desirable approach would be to only allow a maximum of 4 residents per residence subject to waiver based on a finding of undue hardship. Otherwise, new facilities will be designed with outdated “institutional” 16-bed sites and the Division will be constrained to approve them based on existing standards. Existing facilities planning expansion will also be guided by the 16-bed authorization and have no incentive to design smaller, more “normalized” settings. It’s cheaper to “warehouse” residents.

12. Section 5.1.7.1 appears to contemplate mixing of children and adults in the same residence. Indeed, children and adult could share the same bedroom as long as of same sex. See §5.3.7. This is an invitation to abuse. The Division should establish standards in this context in coordination with the Office of Child Care Licensing. Cf. Title 16 Del.C. §5135 and Title 10 Del.C. §1009(j).

13. In §5.2.4, the reference to “glass” could be interpreted to require a glass shower door as juxtaposed to a less breakable and dangerous substitute (e.g. lexan; plexiglass).

14. Section 5.3.1 authorizes crowded conditions. Literally, it requires less floor space for multiple occupancy bedroom than a single-occupancy bedroom. Intuitively, this should be reversed. The minimum floor space in this regulation is much less than that in group homes for persons with mental illness. See 16 DE Admin Code Part 3305, §12.2.2 (80 square feet of floor space per individual required if multiple person bedroom and no more than 2 persons can sleep in bedroom). This equates to 160 square feet per 2-person bedroom. Section 5.3.1.2 allows 4 persons to be placed in a 200 square foot bedroom. The use of tiers of bunk beds for adults (§5.3.4) is also not age appropriate or normal. Crowded conditions are correlated with stress and may promote roommate conflicts since there is little “personal space”. The Division should consider establishing

more enlightened standards akin to group homes in this context and consider a waiver (§25.0) or grandfather authorization to an existing facility if compliance would result in an undue burden.

15. Sections 5.9 and 7.6.7 contemplate the posting of certain phone numbers. Section 4.8 requires compliance with the Patient's Bill of Rights (§4.8) which includes a posting requirement (Title 16 Del.C. §1123). It would be preferable to require the display of a DLTCRP phone number to facilitate resident complaints. By definition, the residents of an IBSER will have diagnoses of autism and other developmental disabilities which are commonly correlated with diminished cognitive capacity. It is therefore important to "simplify" their access to the Division.

16. In Section 7.3, the Division may wish to explore whether carbon monoxide and/or natural gas detectors should be installed and operational. There are dual smoke alarm/carbon monoxide detectors. The Fire Marshall could be consulted.

17. In Section 9.1, an apostrophe should be inserted in "programs".

18. In Section 9.2, consider adding the following final sentence: "If the licensee maintains a website, the same information shall be included on the site."

19. In Section 10.0, the Division should consider including a time period for retention of records. Section 23.2 requires the retention of incident reports for 3 years. By analogy, nursing homes must retain records for 6 years after discharge. [16 DE Admin Code 3201, §9.3] Group homes for persons with mental illness must retain records for 7 years after discharge. [16 DE Admin Code, §8.1]

20. In Section 11.0, comprehensive general liability insurance is required only if mandated by State law or regulation. I am not aware of any such law or regulation. Thus, a facility could operate without liability insurance. There should be an unconditional requirement that the facility maintain general liability insurance.

21. In §§12.2.4.1, 12.2.4.1.2, and 12.2.5.1, delete the references to "criminal justice". An IBSER is not a penal or correctional facility and the skill-set for staff is not criminal justice related.

22. In Section 13.2.6, consider substituting "does" for "must".

23. Section 13.3 does not offer any guidance on the prioritization of training in behavior management policies and procedures. A facility could provide 15 minutes of training in this context with the balance on other topics. It would be preferable to require a minimum number of training hours on behavior management policies and procedures. Moreover, it would be preferable to target not only "policies and procedures" but skills and techniques. The reference could be modified to read "behavior management policies, procedures, and safe and effective techniques". The same comment applies to §13.2 which addresses knowledge of policies and procedures to the exclusion of Mandt-type training.

24. Section 16.1.1.3 contemplates the HRC meeting at least quarterly. This should be changed to monthly to conform to other regulatory sections. The BMC reviews an SBS Plan monthly (§16.2) followed by HRC review (§16.3) and the HRC must review “individual and aggregate clinical data on the frequency of restraint interventions for each individual ...monthly” (§16.8).

25. In Section 16.1.2.3, it would be preferable for the HRC to also review incident reports since §16.1.2.1 contemplates the HRC “determining that residents in care are receiving humane and proper treatment”.

26. There is a reference to “clinical director” in §§16.2. There is no definition of “clinical director” and the position is not listed among the mandatory personnel in §12.0.

27. In §16.4.1, substitute “individual or legal representative”.

28. There is a conflict between §§16.2 and 16.7. The former requires monthly plan reviews. The latter requires monthly plan reviews for the first 90 days followed by quarterly reviews. Monthly reviews would be preferable.

29. Section 18.1 contains multiple references to “non-violent physical intervention”. Intuitively, such an intervention would overlap with “restraint”. There is no definition of “non-violent physical intervention”. A definition should be added or an alternate term adopted. I am unfamiliar with the term “non-violent physical intervention”.

30. Section 19.8.12 bans “seclusion”. Section 18.1 authorizes “time-out”. The definition of “seclusion” (§2.0) is narrow and only applies to a locked room. Therefore, if a facility placed a resident in a closed room with a manually held door mechanism, that would be permitted under the regulation. It would be preferable to define “time-out” and to expand the definition of restraint to cover more than locked rooms.

31. We strongly recommend that Section 19.8 include a prohibition of the use of Wrap Mats. Proactive and positive interventions are more humane and usually more effective with all people, including people with more significant disabilities.

32. Section 19.3 contemplates the development of a comprehensive behavior support plan by an “education, habilitation, or treatment team”. These “teams” are not defined in the regulation.

33. In Section 19.3, the reference to “or medical professional and other relevant professionals” makes no sense. Literally, the regulation requires the following:

1. behavior analyst, psychologist, or “other properly credentialed professional”; and
2. physician or psychiatrist; and

3. nurse practitioner.

OR in lieu of all of these, a “medical professional and other relevant professionals”.

34. Section 19.3.1 refers to “the behavioral clinical professional”. This term is undefined. We suspect it is intended to cover the behavior analyst, psychologist, or other properly credentialed professional referenced in §19.3. The regulation then adopts inconsistent references to a singular, non-fungible behavioral clinical professional (§19.5.5) and plural generic behavioral clinical professionals (§§19.5.1 and 19.5.3). This is confusing. For example, in §19.5.3, can a plan be modified only by the singular behavioral clinical professional on the treatment team defined in §19.3 or by any generic behavioral clinical professional?

35. The reference to “individual, his or her parents or legally authorized guardians or surrogates” in §19.4 should be condensed to “individual or legal representative”. See discussion in Par. 5.

36. In §19.4.4, insert a period after “diffuse”.

37. Section 19.5.5 recites as follows: “Upon initiation of the restraint procedure staff must notify the on-site supervisor, and behavioral clinical professional for approval of the implementation of the procedure.” At a minimum, the comma should be deleted. Moreover, the standard is confusing. Literally, it says staff initiate the restraint and then ask for permission to use the restraint. This is “circular”. Restraint may be justified in an emergency without time to obtain permission from not just 1, but 2 professionals. For example, if a resident initiates head banging, staff should immediately intervene in accordance with procedures outlined in the support plan. If an emergency procedure is contained in a plan, staff should be allowed to implement it and administration should be notified as soon as practicable. Implementation of an emergency procedure in the plan has already been approved through the plan process. See §19.4.

38. In §21.6, insert a comma after “purposes”.

39. In §21.7, requiring a 3-day supply of each resident’s medication is too short a period. A blizzard or other weather-related event could delay access to a pharmacy. Moreover, if a pharmacy is out of a drug, and must order it, a multi-day delay in filling a prescription could easily occur.

40. In §21.8.3, consider substituting “serving” for “service”.

41. At Section 23.0, Incident Reporting should include any use of restraint not otherwise categorically barred by this regulation.

42. Section §23.2 would allow destruction of incident reports after 3 years. This period is too short to protect resident rights. The general 2 year statute of limitation for medical malpractice [Title 10 Del.C. §8128; Title 18 Del.C. §6856] may be temporarily tolled if negligence is not detected or not reasonably discoverable. However, if records are destroyed after 36 months, patients harmed by negligence not readily discoverable may be prejudiced by destruction of records. The statute of limitation for not readily discoverable injuries is 3 years subject to an additional 90-day extension if a Notice of Intent to Investigate is issued. See Title 18 Del.C. §6856(4). The regulation only envisions sharing incident reports with the Division, not the legal representative of the resident.

Therefore, there may be medical omissions and errors which are not discovered for years by legal representatives of residents with cognitive impairments. In many cases, the legal representative will be out of state.

43. Section 23.4 should be amended to include “(d)death of a resident”.

44. Section 23.4.1.2 should require notice to the “legal representative”. See Par. 5.

The Developmental Disabilities Council thanks you in advance for your consideration of our remarks. Please contact us should you have any questions at 739-3333.

Sincerely,


Harline Dennison
Chair

cc. Secretary Rita Landgraf
Kevin Huckshorn, DSAMH
Jane Gallivan, DDDS
State Council for Persons with Disabilities
Governor’s Advisory Council for Exceptional Citizens