April 27, 2017

Renee Purzycki, Social Service Chief Administrator
Office of the Director for the Division of Long Term Care Residents Protection
Delaware Department of Health and Social Services
3 Mill Road, Suite 308
Wilmington, DE 19806

RE: DLTCRP Proposed Neighborhood Homes for Persons with Developmental Disabilities Regulation [20 DE Reg. 766 (April 1, 2017)]

Dear Ms. Purzycki:

The Governor's Advisory Council for Exceptional Citizens (GACEC) has reviewed the Division of Long Term Care Residents Protection (DLTCRP) proposal to do a full revision of the existing standards regulating neighborhood homes for individuals with intellectual and/or developmental disabilities. The proposed regulations will replace the existing regulations which were last updated in April of 2012. In the Summary of Proposed Changes, DLTCRP noted that "Many changes have occurred in the field." Council would like to share the following observations on the revision.

1. The Department of Health and Social Services (DHSS) should consider joint promulgation of regulations by both the DLTCRP and the Division of Developmental Disabilities Services (DDDS). By statute, DDDS is authorized to promulgate regulations covering neighborhood homes. See 29 Del.C. §7909A(c)(1) and (e). In the past, the DLTCRP and DDDS jointly promulgated the neighborhood home regulations. See 15 DE Reg. 968 (January 1, 2012). Sole promulgation by DLTCRP may render the regulations vulnerable to question in any enforcement action.

2. In §1.0, the definition of "authorized representative" merits revision. On the one hand, it appears to limit an "authorized representative" to someone acting on behalf of a resident lacking decision-making capacity in the first and last sentences. On the other hand, it includes someone appointed under a Power of Attorney (POA), Advanced Health Care Directive (AHCD), or supportive decision-making agreement - all of which require the resident to have capacity. This is confusing. The section should be revised to encompass anyone authorized by law to act on behalf of the resident. *Add sentence*

3. In §1.0, definition of "person centered plan", the grammar in the second sentence is incorrect. The list inconsistently includes nouns (people; strategies) and verbs (uses; offers). Compare §7.3 from the Delaware Administrative Code Drafting & Style Manual.

4. In §3.2.1, insert "at least" prior to "annually". Otherwise, a licensee could argue that DHSS can only conduct one inspection annually, i.e., there is a regulatory "cap" of one inspection annually.

5. In §4.2.15, a total ban on firearms on the premises of a neighborhood home could be challenged under the Second Amendment and the Delaware Constitution. See March 14, 2014 News Journal article describing Delaware Supreme Court ruling that the Wilmington Housing Authority (WHA) cannot limit firearms in common areas. See also Title 16 Del.C. §1121(25) and (29). The DLTCRP may wish to seek guidance from the Office of the Attorney General in reference to this issue.

6. The Division should consider adding a subsection to §5.4 which currently contemplates submission of building and renovation plans only to DHSS. Under certain circumstances, the premises would be subject to review by the State Architectural Accessibility Board. See Title 29 Del.C. §7303.

7. The only accessibility references in Section 5.4 are in the context of ramps. See, e.g., §§5.4.6 and 5.4.6.2. This is extremely under inclusive. For example, a ramp for ingress and egress is of little use if doorways are narrow or bathrooms are inaccessible. A general reference at §5.6 is rather cryptic. The Centers for Medicare and Medicaid Services (CMS) Rule contemplates that "the setting is physically accessible to the individual" overall. See 42 C.F.R. 441.710(a)(1)(B).

8. Section 5.4.6 only requires a ramp if accommodating individuals who regularly require wheelchairs. One problem with this approach is that providers have no incentive to have accessible sites and individuals using wheelchairs are disproportionately excluded from the neighborhood home network. A second problem with this approach is that visitors using wheelchairs cannot enter the home. *Add sentence*

9. There is some tension between §5.9.5 (requiring doors to be capable of being opened from either side at all times) and §5.10.7 (requiring lockable doors). The CMS Community Rule promotes resident privacy, including doors "lockable by the individual, with only appropriate staff having keys to doors". See 42 C.F.R. 441.710(a)(1)(B).

10. Section 5.10.12 limits bedrooms to no more than two individuals. It would be sensible to include a subsection noting that residents have some choice in roommates. See Title 16 Del.C. §1121(28). The CMS Rule is even more affirmative: "Individuals sharing units have a choice of roommates in that setting." 42 C.F.R. 441.710(a)(1)(B).

11. Section 6.2 contemplates manual entries in a medication administration record. If electronic entries are permissible in a database (e.g. in THERAP), then this section may merit revision.

12. Section 6.8.3.1 merits review. It generally includes elopement as a reportable incident only if the whereabouts of the individual are unknown and the individual suffers harm. Many behavior plans include restrictions (e.g. line of sight or supervision standards). Section 6.8.3.1 does not account for violations of behavioral plans. Thus, an individual restricted to line of sight due to sex offenses could elope and the agency would not have to report the occurrence.

13. Section 6.8.4.2 characterizes injuries resulting in transfer to an acute care facility as a reportable incident. At a minimum, Council recommends including urgent care facilities in this section. Council understands that a provider may have opted to take injured individuals to urgent care facilities to inferentially avoid reporting incidents. By analogy, the DSCY&F requires its providers to report any injury resulting in medical/dental treatment other than first aid provided on-site. See 9 DE Admin Code 103.15.22 and 103.32.0. This is manifestly a more protective standard.

14. Section 7.4 could be improved by incorporating the ADA standard that there should be no protrusion from the wall in excess of four inches.

15. Section 9.1.5 is overly restrictive in requiring all prescribed medications to be kept locked in a cabinet or lock box. An individual with asthma could not keep an emergency inhaler in his personal possession. An individual with dry skin could not keep a prescription skin moisturizer in his personal possession. The standard is also too rigid if staff are trying to train an individual to monitor and self-administer medications in anticipation of developing greater independence. Restricting access to an individually prescribed medication is not normal and the blanket policy of locking all prescribed medications may violate the CMS Community Rule. If there are less intrusive methods to achieve safety, they should be considered and restrictions only allowed if included in the person-centered service plan. See 42 C.F.R. 441.530 and 441.710(a).

16. Council did not notice a "waiver of standards" provision similar to the current regulation, §12.0. If this is an oversight, the Division may wish to include a comparable provision.

Thank you for your consideration of our observations. Please contact me or Wendy Strauss at the GACEC office if you have any questions.

Sincerely,

Dafne A. Carnright
Chairperson

DAC:kpc

CC: Jill Rogers, DDDS
Steve Groff, DMMA