

April 28, 2014

Sharon L. Summers  
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**RE: DMMA/DDDS Proposed Home and Community Based Services (HCBS) Waiver Renewal Regulation [17 DE Reg. 950 (April 1, 2014)]**

Dear Ms. Summers:

The Governor's Advisory Council for Exceptional Citizens (GACEC) has reviewed the Division of Medicaid and Medical Assistance (DMMA)/Division of Developmental Disabilities Services (DDDS) proposed HCBS Medicaid Waiver Renewal regulations. The GACEC and other councils commented on the draft renewal application in March. Since the content of the waiver renewal has not changed, the GACEC would like to reiterate our earlier comments and add a few additional comments. We would also like to note that although many of our observations are similar to the comments submitted by the other councils, such as the State Council for Persons with Disabilities (SCPD), there are differences so we ask that you take that into consideration as you review our commentary.

In Paragraph 3 of our earlier comments, the GACEC objected to changing the minimum age of eligibility from four to 12 for a number of reasons. We would like to reiterate our objection and remind DHSS that it was prompted to terminate the license and contract of a major DDDS provider on an expedited basis when an investigation team issued a report documenting numerous violations of standards. See Growth Horizons v. Nazario, No. 1:94-cv-00132-RRM (D. Del. August 9 1994) (Stipulation). The rushed termination of a DHSS or Interagency Collaborative Treatment Team (ICT)-funded pediatric provider could be repeated, resulting in the need to provide alternative residential services quickly. If children under 12 are ineligible for the waiver, DHSS would have no available waiver-funded placement options, including shared living, group homes, and emergency temporary living arrangements (ETLAs). Eliminating the waiver eligibility of children between age four and 12 would also undermine the implementation of the DDDS-Division of Services for Children, Youth and their Families (DSCY&F) Memorandum of Understanding (MOU). For example, Section II.B.2 contemplates the availability of DDDS foster home/shared living placements for eligible

children requiring residential services due to abuse, neglect or dependency. Licensed foster home/shared living arrangements are covered by the DDDS waiver.

In Paragraph 10, the GACEC suggested that DHSS consider adding levels of care apart from ICF/IID (Intermediate Care Facility for Individuals with Intellectual Disabilities). Council observed that the DDDS census listed 37 DDDS clients in nursing homes. In addition to our earlier comment, Council would also like to note that DHSS, while funding pediatric nursing home care, has historically confirmed its commitment to “make every effort to support a child’s needs in a community setting if they can be met”. See DHSS commentary at 11 DE Reg. 312 (9/1/07):

The placing of children in any nursing facility needs to be an option for Medicaid eligible children in Delaware. Some children have needs that must be addressed in an inpatient nursing care facility. Medicaid will make every effort to support the client’s needs in a community setting if they can be met. Delaware is fortunate to be able to offer inpatient nursing care facility services to its citizens within Delaware. Previously, Delaware children who required these services had to be placed out-of-state.

It would enable diversion from pediatric nursing facility placement and transition from nursing facility placements, if pediatric waiver-funded residential options were available. DHSS could consider listing both ICF/IID and nursing level of care in the waiver.

The comments from the March 12 GACEC submission are as follows:

1. Council notes that DHSS has included participant direction into its recent waiver initiatives, including personal care/attendant services in both the “Pathways to Employment” waiver [17 DE Reg. 688 (January 1, 2014) and the Diamond State Health Plan Plus waiver [16 DE Reg. 1140 (May 1, 2013)]. CMS explicitly encourages states to include participant direction in their waivers:

CMS urges states to afford all waiver participants the opportunity to direct their services. Participant direction of services includes the participant exercising decision-making authority over workers who provide services, a participant-managed budget or both. CMS will confer the Independence Plus designation when the waiver evidences a strong commitment to participant direction.

At 91. The first explicit objective for the DDDS waiver is to “(p)romote independence for individuals enrolled in the waiver...”. At 4.

In contrast, DHSS certifies (p. 90) that “(t)his waiver does not provide participant direction opportunities.” This rejection of participant direction opportunities is reiterated throughout the document. See, e.g., pp. 5, 41, and 43. The rejection of participant direction opportunities is outdated and confusing in light of other waiver initiatives.

2. The DDDS eligibility regulation [16 DE Admin Code 2100] includes individuals with brain injury. In contrast, the waiver contains zero references to brain injury. It explicitly covers (p. 20) persons with intellectual developmental disability, autism spectrum disorder, and Prader Willi Syndrome. This may be cause for concern, especially among proponents of services for individuals with brain injury who are being clearly omitted from waiver coverage.

3. DDDS proposes (p. 20) no upper or maximum age limit for participants. However, although the current waiver covers children ages four and up, DDDS proposes (pp. 1 and 20) to restrict eligibility to children age 12 and older. This is objectionable and short-sighted for several reasons.

A. Historically, DDDS has offered shared living/foster care for children with families with special interest and expertise in caring for individuals with developmental disabilities. If approved, DDDS could no longer pay for this service on behalf of children under age 12 with the federally subsidized waiver funds.

B. The DDDS enabling statute [Title 29 Del.C. §7909A] imposes a “duty” to provide “foster care placements”, “neighborhood homes”, and “supported living” without any exclusions based on age. In the absence of a statutory authorization to discriminate based on age, DDDS cannot limit its services to certain age groups without violating the Age Discrimination Act and its implementing regulations. When the Division adopted a policy of excluding minors from its group home system in the past, it was “prompted” to settle an HHS (Health and Human Services Office of Civil Rights (OCR) complaint by rescinding the policy. If CMS approves the age restriction in the waiver, DDDS will still have to provide residential and other waiver services to children under age 12. It will simply have to do so with no federal Medicaid match.

C. The DDDS enabling statute [§7909(c)(4)] requires DDDS to provide early intervention services to children ages 0-3. Early intervention services under the DHSS implementation of Part C of the Individuals with Disabilities Education Act (IDEA) include a lengthy list of supports and services. See, e.g. Title 16 Del.C. §212. Moreover, some children with developmental disabilities are eligible for IDEA Part B at birth. The Interagency Collaborative Team (ICT) [Title 14 Del.C. §3124] could prompt DDDS to provide residential programming to such children. If the children are ineligible for the waiver based on age, DDDS will have to provide residential services solely with state funds.

D. In the past, DDDS investigated systemic neglect of young children with developmental disabilities in a nursing facility (Harbor Health). See News Journal articles. The availability of waiver-funded residential options on an emergency basis would be an important resource if such a situation occurs in the future. If the Division limits itself by excluding pre-teens from the waiver, it loses capacity to address this type of situation.

4. Although the waiver document (p. 69) generally suggests that the “State does not impose a limit on the amount of waiver services”, the State imposes (pp. 55-56) an absolute weekly cap of forty (40) hours on supported living. The effect will be “creaming”, i.e., only individuals with modest to mild needs will be able to live in supported apartments or their own homes since support services are capped. Perhaps this is why DDDS projects 825 waiver participants in group homes and only 30 participants in supported living in the first year of implementation. See pp. 148-149. The absolute cap on supported living undermines “choice” and the recently published CMS policy preference for provision of waiver services in integrated settings [79 Fed. Reg. 2948 (January 16, 2014)]. The revised CMS regulation [42 C.F.R. 441.745; 79 Fed Reg. at 3038] recites that “a State may not limit access to services based upon....the cost of services.”

5. The waiver document recites that shared living providers offer residential habilitation services and “are paid at the Medicaid rate for the hours of support they provide up to a maximum of the support hours indicated by the member’s ICAP score.” At p. 139. It is unclear if there is an absolute cap on payment under the ICAP (Inventory for Client and Agency Planning) system. If there is a cap, this may limit “choice” and the ability of high-need individuals to avoid institutional placement.

6. The waiver document (p. 59) contains the following description of neighborhood group homes: “Each resident must have their own bedroom unless they express a preference to share a room”. This is of questionable accuracy. The DDDS neighborhood regulation [16 DE Admin Code 3310, §8.0] does not contain such a standard. Parenthetically, private rooms must be an available option in waivers based on a participant’s choice. See 79 Fed Reg. at 2964.

7. The waiver document authorizes relatives to serve as providers of both “shared living” and “supported living” services. See pp. 2, 55-56 and 61. The CMS templates allows the State to authorize “guardians” to serve as providers as well. Id. However, DHSS has rejected this option. Id. This is unfortunate for several reasons.

A. Other DHSS programs do not bar provision of services by guardians. DDDS has suggested that, in the common situation in which parents are co-guardians of an adult child, a Chancery Court petition could be filed to remove one parent as guardian so the “removed” parent could qualify as a waiver service provider. This is a rather convoluted approach.

B. DDDS has experienced great difficulty in promoting relatives to petition for guardianship when necessary. The exclusion of guardians from serving as waiver providers will simply provide an additional disincentive to relatives considering pursuit of guardianship.

C. One of the purposes of the waiver is to “promote the engagement of family ...supports whenever possible.” At p. 4. This objective is undermined by the ban on guardian providers.

8. The waiver document would apparently disallow any relative from serving as a prevocational provider since the “check-off” for relatives is blank. See p. 43. Likewise, a relative could not provide individual supported employment. See p. 49.

9. The qualifications for a DDDS case manager are very small. See p. 70. Council was unable to locate the basic requirement of a high school diploma.

10. Although there is one outlier reference to diversion from a nursing facility, the waiver generally adopts an ICF/IID (Intermediate Care Facility for Individuals with Intellectual Disabilities) level of care standard. See pp. 3, 20, 31, and 147. Since some waiver participants could lack an intellectual disability (e.g. DDDS autism eligibility regulation does not require intellectual deficit), the State could consider multiple level of care settings for inclusion in the waiver. For example, the December, 2013 DDDS census report lists 37 DDDS clients in nursing homes.

11. The waiver document states several times that the waiver will limit services to participants to those “not otherwise available to the individual through a local educational agency under the Individuals with Disabilities Education Act (IDEA)...”. See pp. 7, 47, and 49. This may violate federal law. See 34 C.F.R. §303.222.

12. The section on restraints (pp. 100 and 103) is not completely accurate. It recites that the sole standard applied by providers is “Mandt” protocols which limit personal restraints to “the one and two person side body hug and the one and two arm supporting technique.” In practice, DDDS has recently authorized some providers (e.g. AdvoServ) to use non-Mandt approved “supine” restraint.

13. The waiver previously included reporting to CMS on the offer of choice between institutional and waiver services. DDDS proposes to delete the reporting while continuing to “track” data. See pp. 2 and 6. This is unfortunate since the election is “key” to a central purpose of the waiver, i.e., to divert individuals from institutions. It would be preferable to maintain data reporting to CMS in this context.

14. CMS requires the State to project the number of participants in the waiver. See 42 C.F.R. 441.745 amended by 79 Fed Reg. 2948, 3038 (January 16, 2014). The reported authorized number of participants in the waiver may be too low. In year 1, DDDS envisions 1,000 participants. See pp. 22-23 and 147. Council assumes this covers the period from July 1, 2014 to June 30, 2015. In contrast, the DDDS December, 2013 monthly census report lists 992 clients already receiving community-based residential services. Council suspects this number will therefore exceed 1,000 prior to the inception of the waiver.

15. The waiver contains “quality” measures which focus on “safety” and absence of abuse/neglect. See pp. 112-119. The waiver would benefit from some measures with a focus on assessing satisfaction with services and overall quality of life.

16. DHSS may need to amend its HCBS waiver standards to include safeguards related to leases and protection from eviction. See 42 C.F.R. §441.530 [revised by 79 Fed. Reg. 3032 (January 16, 2014)] and commentary at

79 Fed Reg. 2960-61.

17. The waiver document (p. 25) contains a countable income cap of 250% of the Supplemental Security Income (SSI) Federal Benefit Rate (FBR). The State could have elected a “300%” standard. Council encourages DDDS to consider adoption of the higher standard.

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

Sincerely,

Terri A. Hancharick

TAH:kpc

CC: The honorable Rita Landgraf, Secretary of DHSS  
Jane Gallivan, DDDS  
Susan Cycyk, M.Ed., Division of Prevention and Behavioral Health Services (DPBHS)  
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