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MEMORANDUM

DATE: August 16, 2010

TO: Ms. Sharon Summers, DMMA
Planning & Policy Development Unit

FROM: Daniese McMullin-Powell, ^{DMP/kt} Chairperson
State Council for Persons with Disabilities

RE: 14 DE Reg. 88 [DMMA Consolidation of E&D, ABI & AL Waivers]

The State Council for Persons with Disabilities (SCPD) has reviewed the Department of Health and Social Services/Division of Medicaid and Medical Assistance's (DMMA's) proposal to submit an amendment to the Elderly and Disabled (E&D) Waiver that combines three existing §1915(c) Home and Community-Based Services (HCBS) waivers [E&D, Acquired Brain Injury (ABI) and Assisted Living (AL)] into one HCBS waiver. The regulations were published as 14 DE Reg. 88 in the August 1, 2010 issue of the Register of Regulations. As background, SCPD provided the Division of Services for Aging and Adults with Physical Disabilities (DSAAPD) with preliminary comments on a May 19, 2010 version of the proposed consolidation of the waivers. DSAAPD provided a July 29 response to each of the paragraphs of the preliminary critique. SCPD is resubmitting its initial observations (with DSAAPD's italicized responses) of the proposed consolidation of waivers as its official comments on the proposed regulations. In addition, SCPD has supplemental observations which are provided subsequent to the italicized responses.

1. The "assurance" section for "Inpatients" (p. 9) recites that waiver services will not be provided to individuals who are inpatients in a nursing home. DSAAPD may wish to add a caveat about respite being offered in such settings. See, e.g., p. 13.

The referenced section is part of the CMS application template and cannot be altered by the applicant.

2. The "assurance" section for "Room and Board" (p. 9) is inconsistent with Appendix I-6 (p. 154). The assurance section would include rent and food expenses for an unrelated live-in personal caregiver while the Appendix categorically excludes such coverage.

The referenced sections are part of the CMS application template and cannot be altered by the applicant. In this case, room and board expenses are allowed under certain circumstances if claimed by the state. The state's option with regard to room and board expenses for unrelated individuals providing live-in care is specified in Appendix I.

3. The “transition plan” section (pp. 12-13) contains an informative list of services available under the current 3 waivers and the services menu under the new consolidated waiver. One significant change for ABI waiver participants is that case management will be switched from private providers to DSAAPD staff. Based on anecdotal criticism of the private case management system, this may enhance the quality of case management services. A second change is that “respite” will be limited to short-term stays in a nursing or assisted living facility. On a practical level, if a participant is interested in “respite” within a home setting, this would be covered as a “personal care service”.

That is correct. The definition of respite has been narrowed, and services previously considered in-home respite will be covered under personal care.

DSAAPD staff assuming case management duties may be familiar with the needs of persons with common physical disabilities and the elderly. However, DSAAPD staff may be less familiar with the specialized needs and services of the ABI population. Although SCPD is supportive of DSAAPD assuming case management duties, Council strongly recommends that DSAAPD commit to train all waiver case managers in the specialized needs and services related to the ABI population. DSAAPD should consider collaborating with DVR which has experience in this context. Moreover, SCPD recommends that DSAAPD require case managers working with individuals with ABI be formally trained as Certified Brain Injury Specialists (CBIS) - this could be achieved within a reasonable timeframe (e.g. 2 – 3 years). Otherwise, the consolidated waiver will be unresponsive to persons with ABI and people may be poorly evaluated.

Regarding respite care, SCPD recommends that a marketing/outreach plan be developed that will proactively inform waiver participants and family members that in-home respite is still available and will be covered under personal care. Anecdotal criticism of the waiver consolidation in this context suggests that many current waiver participants and/or family members believe that respite services will only be provided in institutional settings.

4. Participant questionnaires/surveys will be used as part of the quality assurance process (pp. 24 and 137). This manifests respect for participants and merits endorsement.

The endorsement is noted.

SCPD recommends that the Division consider utilizing the format of surveys utilized by current waiver providers, JEVS and Easter Seals, since they have developed useful surveys which collect meaningful data.

5. In Appendix B-1, Section a., Target Groups (p. 25), there is no “check-off” for “Brain Injury” as a subgroup. SCPD understands from the discussion with Lisa Bond at the June 21 SCPD meeting that CMS may have suggested the lack of the “check-off”. SCPD reiterates the observation since

the omission is not intuitive.

The designation in this section is presented based on instructions from CMS. The structure of the application template in this section lends to confusion with regard to the target population. There should be no ambiguity, however, with regard to the inclusion of persons with brain injury as part of the service population. Narrative is presented under “additional criteria” to highlight and clarify the fact that persons with acquired brain injury are included as part of the target population served the waiver.

SCPD is still uncertain as to why CMS would have made this suggestion and once again reiterates the observation since the omission is not intuitive.

6. DHSS contemplates 1616 participants in years 1-5 of the waiver (pp. 28-29). DHSS is “reserving” 25 slots for individuals transitioning from nursing homes and 5 slots for young adults transitioning from the Children’s Community Alternative Disability Program. The waiver contemplates admission of “all eligible persons” (p. 30). If oversubscribed, a waiting list based on a “first-come-first-served” approach would be established (p. 30).

Based on past utilization patterns, we anticipate that a waiting list will not be needed during the five-year waiver period.

7. DHSS ostensibly had the option of adopting a financial eligibility cap of 300% of the SSI Federal Benefit Rate (FBR). See Appendix B, “Medicaid Eligibility Groups Served in the Waiver” section (pp. 32-33). DHSS adopted a lower (250%) cap. From a consumer perspective, it would be preferable to adopt a higher income cap to encourage employment and promote implementation of the Ticket to Work legislation.

The suggestion is noted. No changes to the cap are planned at this time.

8. The minimum number of waiver services that an individual must require to be included in the waiver is “1” (p. 37). SCPD endorses this provision.

The endorsement is noted.

9. DHSS envisions using its standard “Long Term Care Assessment Tool” to determine whether an applicant meets the necessary nursing facility level of care (p. 38). This could prove problematic if the form is not adapted to identify limitations manifested by individuals with ABI.

DHSS staff will consider this concern in reviewing the assessment tool.

SCPD remains concerned that use of the standard “Long Term Care Assessment Tool” will be an invalid and unreliable tool for assessment of many individuals with ABI. Specialized assessment tools for ABI should be adopted and staff trained in their use. SCPD is reminded of DHSS use of its standard “long term care assessment tool” years ago when evaluating level of care of children for the Children’s Community Alternative Disability Program. The form was not a valid tool for kids.

It had a geriatric bias and did not adequately address mental health and cognition. SCPD predicts that use of a standard “Long Term Care Assessment Tool” for individuals with ABI will prove equally deficient and result in many unjustified determinations of ineligibility. Apart from the assessment tool(s) for level of care, the ABI population may also benefit from use of specialized assessment tools to determine need for services.

10. The description of “adult day services” includes OT, PT, and ST (p. 49) and has 2 levels of service depending on need - “basic” and “enhanced”. The standards are relatively liberal, i.e., the behavior justifying services need only occur weekly:

The service is reimbursed at two levels: the basic rate and the enhanced rate. The enhanced rate is authorized only when staff time is needed to care for participants who demonstrate ongoing behavioral patterns that require additional prompting and/or intervention. Such behaviors include those which might result from an acquired brain injury. The behavior and need for intervention must occur at least weekly.

Standards will remain as presented. However, adjustments may be needed after utilization patterns have been established.

SCPD recommends that the waiver include some provision for supported and competitive employment. In addition, DSAAPD should collaborate with DVR regarding pre-employment services. DVR’s order of selection has resulted in hundreds of individuals being placed on a waiting list. DHSS should assess whether the waiver could include community-based adult day programs such as the TBI Clubhouse Model. Offering solely adult day care and facility-based adult habilitation is an outdated model. It would be preferable to include more robust vocational options for individuals who could benefit from something other than “day care”. SCPD recommends that the waiver provide more flexibility which is not an exclusively facility based medical model that allows people to be able to utilize other community-based programs, including the TBI Clubhouse Model. If the objective of the waiver is to support people in the community and prevent deinstitutionalization, then community-based programs, meaningful employment and volunteer service should be encouraged.

11. The description of “day habilitation service” (p. 50) also specifically mentions individuals with TBI:

Day Habilitation service is the assistance with the acquisition, retention, or improvement in self-help, socialization, and adaptive skills that take place in a non-residential setting separate from the participant’s private residence. Activities and environments are designed to foster the acquisition of skills, appropriate behavior, greater independence, and personal choice. Meals provided as part of these services shall not constitute a “full nutritional regimen” (3 meals per day). Day habilitation services focus on enabling the participant to attain or maintain his or her maximum functional level and shall be coordinated with any physical, occupational, or speech therapies in the service plan. In addition, day habilitation services may serve to reinforce skills or lessons taught in other settings. This service is provided to participants who demonstrate a need based on cognitive, social and/or

behavioral deficits such as those that may result from an acquired brain injury.

This description could be improved by including a reference to “reacquisition” of skills.

A reference to the reacquisition of skills has been added to the definition.

SCPD appreciates the inclusion of a reference to “reacquisition” of skills. In addition, SCPD recommends that the Division adopt reimbursement rates for adult habilitation sufficient to attract quality providers.

12. DHSS specifies that “personal care” can be provided by the following: legally responsible person, relative, or legal guardian (p. 52). See also p. 69. This merits endorsement. However, DHSS later contradicts this authorization by reciting that “(a) representative of the participant cannot serve as a provider of personal attendant services for that participant” (p. 105). This restriction should be deleted. First, it would literally exclude anyone authorized to act on a participant’s behalf through guardianship, a power of attorney or advance health care directive. For persons in assisted living settings who lack competency, it would exclude the closest relatives. See Title 16 Del.C. §§1121(34) and 1122. For other participants, close relatives would be excluded given their authority under Title 16 Del.C. § 2507(b)(2). Finally, the Social Security Administration regulations include a preference for relatives are representative payees. See 20 C.F.R. §404.2021. The exclusion of all such representatives as providers of personal attendant services is overbroad.

The application has been clarified in response to your concern. The language now reads: “A person who serves as a representative of a participant for the purpose of directing personal care services cannot serve as a provider of personal attendant services for that participant.” A guardian, power of attorney, rep payee or any other person can serve as a provider of personal attendant services, but in those cases, another individual would need to act as representative for the more narrow purpose of directing the personal care. This separation, for example, would allow for two signatures on time sheets, one from the employer (the participant or his/her representative) and one from the employee. Note that the waiver allows for non-legal as well as legal representatives for purposes of directing personal care.

13. DHSS requires all persons providing personal care to complete a training regimen in the absence of an emergency (App. C-1/C-3; p. 52). See also p. 71. This is ostensibly overbroad. For example, it is possible that a relative has been competently providing this service to a participant for years.

It is understood that experience and skill levels will vary and this will be taken into consideration in the development of training standards.

14. The service specifications for assisted living include 9 different levels of reimbursement depending on the participant’s needs (p. 56). This merits endorsement. It should facilitate continued residency in an assisted living setting since such facilities could rely on enhanced

services to deter “dumping” to nursing homes.

The endorsement is noted.

15. The service specifications for “cognitive services” (p. 57) are critical for persons with ABI. The norm of 20 annual visits may be too restrained. Moreover, the criteria could be enhanced by including some forms of AT (e.g. biofeedback equipment) and also including OT and ST supports. For example, language development could be considered a component of “cognitive services”. SCPD recognizes that DME is separately covered under the heading of “specialized equipment and supplies” (p. 61). However, the service specifications for adult day services includes OT, PT, and ST supports (p. 49). By CMS regulation, OT, PT, and ST includes equipment used to facilitate the therapy. Thus, “DME” could be incorporated into other service specifications.

With regard to the number visits, it is expected that a maximum of 20 visits per year will meet the needs of most participants. Note, however, that under the Waiver, DSAAPD case managers may authorize service request exceptions above that limit. With regard to assistive technology (AT) supports, DSAAPD staff will ensure that when such needs are documented, that those needs are reflected in an individual’s care plan. When applicable, AT supports would be paid for under the Medicaid State Plan. Those AT supports which are not reimbursable under the state plan could be covered under the Waiver as Specialized Equipment and Supplies.

16. The list of providers of cognitive services (p. 58) omits licensed professional counselors of mental health (Title 24 Del.C. §3030). DHSS should consider whether to add a reference. It would also be appropriate to add “advanced practice nurse” [Title 24 Del.C. §1902(b)(1)].

These are helpful suggestions that DHSS will research and consider for inclusion in the future amendments to the waiver.

SCPD believes DHSS has the discretion to address this section as part of the amendment to the waiver. Council believes that the recommendation is fairly “benign” and is submitting the recommendation so it could be included in this amendment to the waiver, not a future amendment.

17. The criteria for personal emergency response system (PERS) allows the participant to connect not only to a response center but also “other forms of assistance” (p. 59). This is preferable since some systems allow a participant to program the system to contact relatives, friends, neighbors, and 911 in sequence rather than an expensive and impersonal call center. However, the cost tables (pp. 160-161) appear to contemplate almost exclusive enrollment (740+ participants) in monthly monitoring services.

This service alternative was added in response to SCPD’s recommendation during the waiver renewal process last year. DHSS is hopeful that the expanded emergency response definition will provide more options for participants and at the same time lead to cost savings in the Waiver

program. After DHSS enrolls providers of non-monitored emergency response systems in the Waiver program and participants' utilization patterns are established, the cost projections may need to be adjusted accordingly.

18. DHSS may wish to consider requiring maintenance of service plans beyond the minimum 3 years (App. D-1; p. 86).

The referenced language is part of the application template and cannot be changed by the applicant. In actuality, plans are maintained for a longer period of time.

SCPD is dubious that DHSS would not have discretion to include a longer timeframe in the template. Therefore, Council continues to recommend requiring maintenance of service plans beyond the minimum 3 years.

19. DHSS contemplates a minimum of 4 contacts annually (2 contacts from a case manager and 2 contacts from nurse) with each participant (p. 88). This standard is arguably too infrequent.

This minimum standard is established so that in times of critical staff shortages (such as those that might occur during a spending or hiring freeze), the state would not be out of compliance with waiver requirements.

SCPD believes that adopting this minimum standard so the state would not be out of compliance with the regulations is not acceptable. It also infers that during times of economic restraint, case manager support positions would not be filled which would negatively affect case management levels. SCPD recommends that DHSS contact OMB and solicit agreement that waiver case management support positions will be filled even during hiring freezes so the safety of individuals with disabilities and the elderly who use these waiver services is not jeopardized.

20. In the "fixing individual problems" section (p. 100), it would be preferable to include a reference to involving the participant in the resolution of the concern.

In this section, fixing individual problems does not typically refer to fixing an individual's problem, but rather, fixing a single-occurrence or isolated administrative problem (as opposed to a systemic one). This language is used as part of the application template.

21. The DHSS table for participant direction of services contemplates 0 participants directing their own services in year 1 of the waiver (App. E-1; p. 111). This should be reconsidered. DHSS envisions 1616 waiver participants in year 1 (p. 156).

The E&D Waiver is currently approved for a five-year period beginning 7-1-09. This amendment has an effective date of 12-1-10, which is five months into Year 2 of the approved waiver period. Because Year 1 of the waiver concluded on 6-3-10, the table correctly indicates that no participants self-directed services during that period.

22. In the sections on grievances, critical events, and quality assurance, DHSS may wish to consider adding a reference to CLASI. CLASI is mentioned on p. 115 as a resource in the context of fair hearings. See, e.g., Title 16 Del.C. §§1102(7), 1134(e)(f)(g), and 1119C(b) [applicable to nursing and assisted living facilities].

This section of the application was not addressed as part of the amendment. The suggestion will be kept on file for future reference.

SCPD believes DHSS has the discretion to address this section as part of the amendment to the waiver. Council believes that the recommendation is fairly “benign” and is submitting the recommendation so it could be included in this amendment to the waiver, not a future amendment.

23. There are several references to the Ombudsman and DLTCRP in the quality assurance context. However, the references uniformly limit the Ombudsman to “non-abuse related complaints”. See, e.g., pp. 117 and 120. To the contrary, the Ombudsman is statutorily required to address abuse and neglect concerns. See Title 16 Del.C. §1152(1)(5). Although DHSS has attempted to eschew this responsibility through an MOU, the validity of the MOU could be questioned.

This section of the application was not addressed as part of the amendment. The comment will be kept on file for future reference.

SCPD believes DHSS has the discretion to address this section as part of the amendment to the waiver. Council believes that the recommendation is important and is submitting the recommendation so it could be included in this amendment to the waiver, not a future amendment.

24. Appendix G-2 (pp. 122 and 123) recites that “the State does not permit or prohibits the use of restraints or seclusion.” Although Council would prefer that this were accurate, the statement is inconsistent with Title 16 Del.C. § 1121(7) and 16 DE Admin Code Part 3201, §6.3.8.4.

This section of the application was not addressed as part of the amendment. The comment will be kept on file for future reference.

SCPD believes DHSS has the discretion to address this section as part of the amendment to the waiver. Council believes that the recommendation is fairly “benign” and is submitting the recommendation so it could be included in this amendment to the waiver, not a future amendment.

25. The “medication administration” section (p. 126) is underinclusive. It refers to an exception to the Nurse Practice Act for assistance with medications by persons who have completed a training course. However, it fails to include a reference to Title 24 Del.C. §1921(19) or §1921(4); and 24 DE Admin Code, Part 1900, §§7.7.1.4 and 7.9. Competent individuals can

generally delegate administration of medications to personal attendants.

The referenced section of the application pertains only to the administration of medication in licensed assisted living facilities.

SCPD reviewed this section and believes that it is not clear that it literally refers only to the administration of medication in licensed AL facilities. DHSS may want to clarify that it only applies to AL facilities.

26. The reimbursement rate for personal care is listed as \$7.09 per 15-minute unit (e.g. \$28.36/hr.). The reimbursement rate for respite is listed as \$6.91 per 15-minute unit (e.g. 27.34/hr.). See p. 159. Clarification would be appropriate. Council does not believe that non-agency personal attendants and respite providers are paid at these rates.

Personal care costs for Year 1 are estimates based on home health agency rates. The cost estimates in subsequent years are reduced significantly to account for the fact that personal care providers may include home health agencies, personal assistance services agencies (PASA), and personal attendants.

27. Consistent with discussions with DSAAPD, personal care service specifications provide a guideline of 25 hours per week, but that there are not necessarily any service limits. SCPD continues to recommend that the 25 hour guideline be deleted.

The application itself does not specify service limits with regard to personal care. We will consider your comments when developing personal care service authorization guidelines.

SCPD would like to be included in the development of the personal care service authorization guidelines.

28. SCPD recommends more frequent assessment of waiver implementation, especially during the initial 12 months of implementation after December 1, 2010. Since waiver amendments can be submitted at any time, frequent data collection and assessments are critical to determine the emerging needs of participants in the waiver. For example, regular reports to the SCPD Brain Injury Committee (BIC) and/or SCPD would be appropriate. If monthly data were compiled, this information could be shared with the SCPD to facilitate review.

In addition, SCPD recommends that DHSS disaggregate the data collection/satisfaction survey responses for people with ABI because there could be an example in which, overall, people in the new consolidated waiver are very satisfied. However, there could be a subset of people with ABI in the consolidated waiver who are 100 dissatisfied and the overall survey of participants would not capture this data. Quality assurance methodology needs to capture useful and meaningful data.

Thank you for your consideration and please contact SCPD if you have any questions or

comments regarding our observations or recommendations on the proposed regulations.

cc: The Honorable Rita M. Landgraf
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Governor's Advisory Council for Exceptional Citizens
Developmental Disabilities Council

14reg88 waiver amend 8-10