MEMORANDUM

To: DMMA Planning, Policy & Quality Unit

From: Brian J. Hartman, Project Director, Disabilities Law Program

Re: Comments on HCBS Transition Plan, 19 DE Reg. 782 (February 1, 2016)

Date: March 14, 2016

I am submitting the following comments on the Delaware Statewide Transition Plan in response to the DMMA solicitation appearing at 19 DE Reg. 782 (February 1, 2016). Given time constraints, the comments should be considered preliminary and non-exhaustive.

**General:** Each page in the State Transition Plan (“STP”) has been dated “February 1, 2016”. However, many pages have not been updated and refer to plans and expectations from 2015. This is confusing. Perhaps each page should have a “revision” date so it would be clear that some original pages reflect planning as of March, 2015 and some pages contain updated information as of a later date.

p.1: In the “Introduction” section, DHSS could consider embellishing the “core values” discussion by including some explicit references and/or quotes from the DD Bill of Rights (16 Del.C. Ch. 55) and the Employment First Act (19 Del.C. §§740-747) confirming State public policy. Proponents of the “status quo” and interest groups espousing a “low expectations” approach could easily overlook the consistency in values contained in State law and the CMS “Community Rule”.

Consider the following examples:

§5502. Persons diagnosed with intellectual disabilities or other specific developmental disabilities have the right to proper medical care and physical restoration and to such education, training, habilitation, and guidance as will enable them to develop their abilities and potentials to the fullest possible extent, no matter how severe their disability may be.
§5503. Persons diagnosed with intellectual disabilities or other specific developmental disabilities have a right to strive for productive work in meaningful occupations, economic security and a decent standard of living.

§741. All persons, including persons with disabilities, have a right to the opportunity for competitive employment. In order to achieve meaningful and competitive employment for persons with disabilities, employment opportunities in fully-integrated work settings shall be the first and priority option explored in the service planning for working-age persons with disabilities.

§743. It is hereby declared to be the policy of this State that competitive employment in an integrated setting shall be considered its first and priority option when offering or providing services to persons with disabilities who are of working age. All state agencies that provide services and support to persons with disabilities shall follow this policy and ensure that it is effectively implemented in their programs and services.

Moreover, the Plan contains many references to a goal of promoting employment paying at least the “minimum wage” (pp. 4, 5, and 6). As an update, a reference to current State legislation to raise the minimum wage could be mentioned. S.B. No. 39 passed the Senate in January, 2016 and represents an initiative which would benefit many individuals enrolled in HCBS waivers.

p. 3: It would be informative to update the 2014 figures on enrollment in the DDDS waiver and DSHP and DSHP+ programs (by footnote or otherwise). It would also be informative to provide recent statistics demonstrating DHSS success in transforming its service delivery system to one which is predominantly community-based. See Secretary’s FY17 JFC presentation, p. 5 (http://www.dhss.delaware.gov/dhss/fiscalyearjfchearingssecretary.pdf).

p. 11: In two documents, CMS requested DHSS to provide information concerning plans and strategies to assure ongoing compliance after March, 2019:

Please provide a step-by-step approach (supported with precise timeframes) for both provider remediation and compliance activities (based on a provider’s approved CAP), and ongoing compliance after the March 2019 deadline.

September 24, 2015 CMS letter to DMMA, p. 2. [emphasis supplied]

Please amend the STP to provide a step-by-step approach (supported by precise timeframes) for both provider remediation and compliance activities (based on the provider’s approved CAP), and ongoing compliance after the March 2019 deadline. In the approach, please describe how often monitoring will occur, whether it will be integrated into existing licensing processes, and what specific tools and processes the state will use to ensure compliance of settings.

STP, Attachment 5, p. 2. [emphasis supplied]
I infer that CMS would prefer to deter “backsliding”, i.e., achieving compliance by March 17, 2019 but discontinuing efforts to promote continuing compliance after that date. In contrast, the Plan contains an “end date” of March 17, 2019 throughout the document. See, e.g., pp. 11 and 18. Page 70 would also benefit from clarification that activities would extend beyond March 17, 2019.

p. 11: There is some “tension” between identification of a March, 17, 2019 end date to “implement remediation strategies” on p. 11 with a different targeted “end date” of July 31, 2018 for implementation of provider CAPs on other pages. Compare pp. 37, 56, 62, 68 and Attachment 5, p. 3.

pp. 13-14: The list of State laws, regulations, and policies on pp. 13-14 could be updated based on the content of the STP, Attachment 6, including a reference to the IBSER regulations. [Attachment 6, p. 26] See also p. 39.

p. 15: The IBSER-regulated program should be added to the bulleted list of settings subject to review.

pp. 15-17: There are several references to planned development of an appeal process for providers to dispute findings. Since reports with findings are due by March 31, 2016 (p. 26), the appeal process should have been developed by now and should be described. The time line for development is omitted from the matrix on p. 26.

p. 17: The following statement is contained on this page: “Any Corrective Action Plans and other strategies identified in Phase 4 must be fully implemented by March 17, 2019 so that the entire waiver service delivery system will be compliant with the Community Rule.” This date does not conform to the July 31, 2018 target adopted in other sections. See comments on p. 11 above.

p. 23: The review of DDDS and DLTCRP regulations by these divisions is “underinclusive”. The DDDS waiver covers children between the ages of 12-17 (p. 3). Such children served in an entity (AdvoServ) covered by the adult IBSER regulations are covered by DSCY&F regulations. See 16 DE Admin Code 3320.2.0 and 9 DE Admin Code 105. The DSCY&F regulations have not been identified for review.

p. 23: The following recital appears on this page: “Advisory Council to DDDS will review and must approve any DDDS strategies for remediation.” The Advisory Council should not be accorded the authority to “trump” or “overrule” DDDS decisions. Under its enabling law (29 Del.C. §7910), it an advisory body to DDDS.

p. 24: CMS questioned the “distant” target of January 13, 2017 to complete legislative revisions. [Attachment 5, p. 3]. The State is now extending that “distant” date for legislative changes to March 17, 2019 (p. 24). The State completed its review of the landlord-tenant code by April 30, 2015 (p. 22) and contemplates completion of its review of other laws by March 31, 2016. It should not take three (3) years to effect legislative revisions. The STP would also benefit from some interim targets rather than a single global target (March 17, 2019) for all legislative changes.
p. 24: The “end date” for DDDS to revise the monitoring tool used by the DDDS Office of Quality Improvement to include the HCBS settings requirements is July 1, 2016 (pp. 24 and 28). There is some “tension” between that Office conducting “look behind” reviews of providers by May 31, 2016 (p. 26) and development of the monitoring tool by July 1, 2016 (p. 39). Ideally, it would be preferable for the Office to have finalized and been trained in using its assessment tool to assist with the “look behind” assessments to be completed by May 31, 2016.

p. 26: The May 31, 2016 date to complete “look behind” reviews (p. 24) is different than the date to complete “look behind” reviews (March, 2016) identified on p. 34.

p. 27: The status of the new home being built with an expected December 31, 2016 move-in date is not provided. See also pp. 38 and 56 and Attachment 5, p. 4. It would be useful to know the status of construction.

p. 29: Activities to “begin” correction of regulations and policies will not occur until October, 2016. This is ostensibly too long to begin work. It is also inconsistent with the January 1, 2016 date to start changing regulations and policies listed on p. 24. See also November, 2016 date on p. 58.

p. 32: It would be interesting to assess any patterns between surveys completed by guardians versus those completed by waiver participants themselves.

p. 32: The setting (AdvoServ) regulated by the IBSER regulation is omitted from the bulleted list of provider settings to be reviewed. Compare Attachment 6, p. 26.

pp. 34-35: It would be appropriate to add the DDDS Human Rights Committees as a source of consultation on provider compliance with the CMS “settings” regulation, client rights, and restrictions of rights in behavioral plans. The HRCs review an aggregate of hundreds of plans annually as well as rights complaints. See HRC policy published at http://www.dhss.delaware.gov/dhss/ddds/policy_administrative.html.

p. 35: The STP recites that a Behavior Support Plan may authorize deviation from the HCBS Final Rule, including authorizing restrictions of rights, only if there is “informed consent of the individual or legal representative (see 42 CFR §441.301( c)(2)(xiii)(G)).” In practice this is not accurate since many DDDS waiver participants lack capacity to consent and lack a guardian or other substitute decision-maker.

p. 35: The behavior plans of DDDS clients covered by the IBSER regulations often deviate from the bulleted plan requirements, including adoption of generalized “levels” systems to earn access to preferred food and privileges. Cf. Attachment 6, p. 32 (setting standards not compliant). DDDS review which exceeds the minimum sample standard would be appropriate.
p. 36: The bulleted section could be improved by requiring some interim milestones towards achieving compliance. This would be consistent with the “quarterly on-site visits” contemplated on p. 37. As written, a CAP could simply have a single date (e.g. July 31, 2018) which undermines meaningful progress assessments. For example, an interim benchmark might be compliance by 25% of the provider’s settings within 3 months, compliance by 50% of the provider’s settings within 6 months, etc.

p. 38: The STP (p. 54) contemplates identification of out-of-state sites in which Delaware waiver participants may live by September 30, 2015. There is some “tension” between that date and following recital (p. 38):

Several DDDS waiver members are supported in residences in other states that were determined to best meet their specialized needs. DDDS has begun the process of communicating with (those) states for this purpose.

If would be preferable to provide the current status and identify an “end date” for this process.

p. 39: The STP recites that DLTCRP regulations “largely involve attributes of the physical plant in which the services are delivered, as opposed to addressing the experiences of the individuals who are receiving the services.” This is inaccurate. Compare, e.g., 16 DE Admin Code 3320, §§5.0 and 9.0-26.0.

p. 40: The references to “Plan of Improvement”, “plan of correction”, and “Plan of Correction” should be converted to “Corrective Action Plan” for consistency with the rest of the STP. Compare pp. 18, 27, and 45. The word “division” should also be capitalized.

p. 42: Per comments on p. 23 above, DSCY&F regulations should be added to the list of standards to be reviewed.

p. 42: The STP recites that “(a)dditional materials will be added to the review as they are identified.” The current list include the “Landlord-Tenant Code”. See also p. 50. Legislation (S.B. No. 179) to amend Delaware’s Fair Housing and Landlord-Tenant Codes has been introduced to ban discrimination based on “source of income”. Under current law, a landlord can refuse to rent to a tenant based on SSI or SSDI being their source of income. Delaware has 27,404 SSDI (“disabled workers”) beneficiaries and 16,687 SSI beneficiaries. Almost all DDDS HCBS waiver participants and a high proportion of DSHP+ participants are SSI beneficiaries. The legislation would obviously facilitate implementation of the HCBS Community Rule for individuals with leases. The legislation has been supported by several State agencies, the DLP, AARP, League of Women Voters, and a host of other organizations. It passed the Senate in January, 2016. In contrast, the Delaware Department of Health & Social Services has declined to support the bill, adopting a “neutral” position. S.B. No. 179 should be added to the list of initiatives for review and DHSS should reconsider its lack of support for the legislation.
p. 43: The State recites as follows: “DMMA will develop an acceptable response rate for the provider self-assessment.” This is somewhat vague. It would be preferable to include a specific percentage figure. The actual response rate was high. See p. 65. See also Attachment 5, p. 1.

p. 43: The State indicates that the Governor’s Commission on the CBAID will assist in conducting look-behind reviews “as determined appropriate”. Since the end date for this activity is February and March of 2016 (p. 55), the State should be able to provide greater specificity in describing the Commission’s role.

p. 45: The State identifies a March 17, 2019 target date for completion of Corrective Action Plans. This is inconsistent with the July 31, 2018 date identified in other sections of the STP. See comments on pp. 11 and 17 above.

p. 45: Grammar should be corrected as follows: “The State...to continuously monitoring participant health....”

p. 45: Identifying an “end date” of March 17, 2019 and no activities after March 17, 2019 is inconsistent with CMS directives to include activities after March 17, 2019. See comments on p. 11 above.

pp. 52-53: The Plan envisions an end date of July 31, 2016 to develop remediation strategies for laws which are not fully compliant. It then adopts a March 17, 2019 end date for legislative changes. This is almost three years. If the strategies are completed by July 31, 2016, it should not be difficult to prepare legislation over the next six months for introduction by February 1, 2017. Instead, the Plan identifies no work on remediation activities between August-October, 2016, i.e., “implementation of all remediation activities will begin no later than November 2016” (p. 58).

p. 56: The timetable envisions providers being given “findings” by April 30, 2016 in anticipation of providers submitting a Corrective Action Plan immediately or within a few days (e.g. between April 30 - May 6). This is ostensibly unrealistic.

pp. 70-71: It would be preferable to clarify that described activities would extend beyond March, 2019. See comments on p. 11.

Given the 82-page length of Attachment 6, the following observations are based on an abbreviated review of content.

Attachment 6, pp. 2-9. The section omits any reference and consideration of “Adult Day Care” regulations, 16 DE Admin Code 4402. I understand some DDDS clients are served in this setting. The section also omits any consideration of the standard DDDS provider contract. The standard FY16 DDDS “contract” with appendices for day programs is published on the Web. See http://dhss.delaware.gov/dhss/ddds/providercontract.html. Appendix A (Divisional Requirements: Day & Residential Program Services) contains many standards.
Attachment 6, p. 7: The matrix omits the PROBIS and HRC policies. The PROBIS and HRC committees are key DDDS entities protecting waiver participants from unjustified rights restrictions and chemical, mechanical, and physical restraints. See http://www.dhss.delaware.gov/dhss/ddss/policy_administrative.html.

Attachment 6, p. 7: The “day hab” section of the matrix has a “freedom from coercion and restraint” section. It omits the IBSER regulations which cover the day program of the covered entity. See 16 DE Admin Code 3320.3.0 (definition of “resident”). The IBSER regulations address restraint in detail. See 16 DE Admin Code 3320.20. The Plan focuses on the IBSER regulations only in the context of residential settings (pp. 26 and 29).

Attachment 6, pp. 10-18: If there is a standard DDDS contract with appendices for providers of prevocational services, it should be included in the matrix and assessed for compliance with the CMS Community Rule. See comments on Attachment 6, pp. 2-9.

Attachment 6, pp. 19-43: If there is a standard DDDS contract with appendices for providers of residential services, it should be included in the matrix and assessed for compliance with the CMS Community Rule. See comments on Attachment 6, pp. 2-9.

Attachment 6, pp. 19-43: Although the IBSER regulations are mentioned, an accurate assessment of domains can only be completed through a review of other documents. For example, in the “food domain” (p. 39) the program regulated by the IBSER regulation has “levels” systems in which preferred foods may have to be “earned”. Similarly, in the “choice” domain (p. 32), phone access at preferred hours may have to be “earned”.

Attachment 6, p. 22: The State assesses itself as compliant with the following domain: “The individual receives services in the community with the same degree of access as individuals not receiving Medicaid HCBS.” It solely cites the following regulation as documentation of compliance: “4.2.1.5. The individual has access to all areas of his/her environment.” I do not understand how this regulation can serve as the sole basis for the State’s conclusion that it meets the domain.

Attachment 6, p. 35: A corollary to the “choice of roommates” standard is whether an individual could opt to have no roommates (e.g. live alone). This is partially addressed on p. 24 but is not very clear. In practice, my impression is that few waiver participants are offered the option of their own unit.

cc: Kyle Hodges  
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7