

December 2, 2008

Ms. Marianne Smith, Director
Division of Developmental Disabilities Services
Woodbrook Professional Center
1056 S. Governor's Ave. – Suite 101
Dover, DE 19904

Dear Marianne,

The State Council for Persons with Disabilities (SCPD) has reviewed the Division of Developmental Disabilities Services' (DDDS) final Human Rights Committee (HRC) policy. As background, the Disabilities Law Program (DLP) submitted a 10-paragraph critique of the DDDS HRC policy on March 27, 2008. SCPD sent a May 1 letter to DDDS endorsing the DLP critique. DDDS then issued a July 28 revised draft of the HRC policy and SCPD sent a September 16, 2008 letter with comments on the revised draft. SCPD has the following observations on the final policy.

March Comments

1. SCPD recommended clarification of whether the HRC would review rights restrictions for both residential and non-residential DDDS clients. We noted one option would be to cover both residential clients and those enrolled in day programs. DDDS incorporated the latter option into Section V.A.4.
2. SCPD recommended incorporating the concept of a surrogate decision-maker (e.g. by power of attorney) into Section IV. We also recommended deletion of references to the authority of "a person who has otherwise exhibited special care and concern." DDDS incorporated a reference to "legally recognized agents" within Section IV.F.1 and deleted references to "person who has otherwise exhibited special care and concern".
3. Council recommended reconsideration of a provision contemplating HRC review of "all individual rights restrictions". Consistent with Section V.A.4, it appears that the HRC jurisdiction remains broad. However, there is a cross reference to the DDDS Individual Rights Review Policy. SCPD lacks a copy of that policy and therefore respectfully requests a copy of such policy.
4. SCPD recommended at least adding a preference for including a DLP representative on the HRC. Section V.H was added to provide the DLP the option of serving on each HRC.
5. Council recommended addressing HRC member liability. The new policy does not directly address liability but diminishes exposure by making the community-based HRCs advisory.

6. SCPD recommended deletion of the following sentence: “Any member involved in the development of a proposal or issue to be addressed by the HRC is excluded from voting on the respective topic.” DDDS deleted the sentence in favor of a more functional conflict standard. See Section V.P.

7. SCPD recommended adoption of consistent standards in HRC and PROBIS policies. Unless the PROBIS policy has been revised, there is still some lack of clarity. For example, the HRC policy contemplates “re-review” within 365 days (Section VI, Table, Par. 6; Section IV.A.5), but also contemplates HRC review only after PROBIS review (Section V.A.1) which could occur beyond one year.

8. SCPD recommended clarification that the HRC reviews more than “consent”. DDDS incorporated a broader review mandate into Sections V.A 1; V.A.3; V.A.4; and Section VI.

10. SCPD recommended clarification that the HRC will continue to review psychotropic medications. HRC review of some drugs is incorporated into Sections IV.C and V.A.1.

10. SCPD recommended correction of a grammatical error. Section V.D was revised. However, there is a new grammatical error in this section, i.e., “person” should be “persons”.

September Comments

1. SCPD noted that federal ICF/MR regulations required at least the Stockley HRC acting as more than an “advisor”. Sections V.A.1.a and VI, Table, Par. 4 contemplate broader jurisdiction for the Stockley Center HRC. However, all HRCs still act in an advisory capacity only. See Section VII.

2. SCPD recommended authorization for the HRCs to make systemic recommendations to the Division Director and Deputy Director. DDDS maintained a model in which HRCs issue recommendations only to the Executive Director of Stockley, Director of Community Services, and Director of Special Populations. See Sections V.A.6; V.L; and VII.

3. SCPD is still concerned with limiting HRC review of “medication for the sole purpose of behavior management in the absence of a psychiatric diagnosis”. See Sections IV.C and V.A.1. Council noted that ICF/MR regulations require the Stockley HRC to review “drug usage” irrespective of presence or absence of psychiatric diagnosis. We also noted that physicians do not generally prescribe psychotropic medications without a psychiatric diagnosis. DDDS incorporated a broader review provision (Section V.A.1) for the Stockley HRC. It did not change the jurisdiction of the community-based HRCs. A literal interpretation of the above standard will eliminate 80-90% of the NCC HRC reviews. For perspective, SCPD checked the diagnoses of all cases reviewed by the NCC HRC at its latest (October 16, 2008) meeting. Of the 31 medication reviews, 26 clients had psychiatric diagnoses and the remaining 5 had diagnoses of autism only. Under the new HRC policy, the HRC would not review usage of psychotropic drugs for 84% (26/31) of the DDDS clients previously subject to review. If autism is considered to be a psychiatric diagnosis, then it would be 100 percent of clients.

4. SCPD shared five concerns related to the surrogacy section. DDDS overhauled the section.

5. SCPD identified an incomplete note. This was corrected.

6. SCPD identified two redundant paragraphs. This was corrected.

7. SCPD noted that the requirement that each HRC have five members could be problematic since the NCC HRC

has not had five members in recent memory. DDDS changed the minimum composition to four members. See Section V.H.

8. SCPD recommended establishing a quorum of 1/3 of the membership in lieu of a 51.0% standard. The “51%” standard was retained. See Section V.P. This means that 3 of the 4 NCC HRC members must be present for a quorum.

9. SCPD recommended affirmatively memorializing the existing practice of allowing the DLP representatives to include brief information about HRC activities in DLP federal reports. DDDS added a conforming authorization to Section V.F.

10. SCPD recommended DDDS consideration of whether it collects information described in Par. 6 of Exhibit C. There was no change in the form.

SCPD certainly appreciates that DDDS incorporated many edits prompted by the Council’s commentary. As a result of our November 13, 2008 SCPD Policy & Law Committee meeting, it is Council’s understanding that the DDDS representative will be following-up to determine the interaction of the HRC and PROBIS policies in the context of our recommendation in Par. 7 of the March comments. In addition, the DDDS Advisory Council will be following up on the underlined concern identified in Par. 3 of the September comments.

Again, thank you for your consideration of Council’s comments and please contact SCPD if you have any questions regarding our latest observations on the final policy.

Sincerely,

Daniese McMullin-Powell, Chairperson
State Council for Persons with Disabilities

cc: Mr. Brian Hartman, Esq.
Mr. Anthony Horstman
Ms. Mary Anderson
Ms. Chris Long
Governor’s Advisory Council for Exceptional Citizens
Developmental Disabilities Council

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