September 16, 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) proposal to amend its Human Rights Committee (HRC) policy. SCPD has the following observations.

First, Sections II. and IV. Definitions, Advisory Capacity, relegate the HRC to simply an advisory panel "which does not have the authority...to take definitive actions or render decisions." At least in the context of the Stockley HRC, federal ICF/MR, federal regulations require the establishment of an HRC with the authority to "review, approve, and monitor" restrictive programs and "insure" that such programs are conducted only with proper consent. See attached 42 C.F.R. 483.440((f). DDDS cannot reduce the Stockley Center HRC to a mere advisory body without violating the federal regulation.

Second, Sections II., V.C., and V.K. limit the HRC to an advisory role to the Stockley director and directors of community services/adult special populations. This is inconsistent with the attached DDDS Rights Complaint policy (rev. March, 2005), Section VI, which contemplates the HRC submission of comments for the Division Director's review. Since the HRCs may be making statewide or systemic recommendations, it makes sense to allow them to advise the Division Director, Deputy Director, and other administrators within the agency.

Third, in Section IV., Definitions, Level II Behavior Interventions, the definition of a behavioral intervention subject to HRC review literally excludes medications in the absence of a psychiatric diagnosis. As a practical matter, physicians do not prescribe a psychotropic drug without a psychiatric diagnosis. Indeed, the NCC HRC reviews the administration of drugs to hundreds of DDDS clients annually and a psychiatric diagnosis is almost always present. The ICF/MR regulation requires the Stockley HRC to review "drug usage" irrespective of the presence or absence of a psychiatric diagnosis. See attached 42 C.F.R. 440(f)(3)(iii).

Fourth, in Section IV., the standards related to a "surrogate" are problematic in several respects.

A. The reference to HIPAA is odd. HIPAA addresses access to medical records, not authority to consent to treatment. The only reason a surrogate is material to the HRC policy is in the context of authority to consent to behavioral interventions and rights restrictions. Inserting criteria related to access to records is misleading.

B. Par. 2 should be amended to require written documentation of oral consent. See Title 16 Del.C. §2507(b).

C. In Par. 3, the reference "for the purpose of requesting and receiving protected health information" "muddies the waters". The HRC is interested in authority to consent, not access to records. Consistent with Title 16 Del.C. §2507, the surrogate may consent to treat or withhold treatment. This is the material reference for inclusion in the policy.

D. Par. 4 should be deleted as surplusage. If someone has a guardian, this is covered by Par. 1. For the same reason, the last sentence in Par III in Exhibit B should be deleted.

E. For DDDS clients in licensed long-term care facilities, including group homes, the surrogate section should include a reference to Title 16 Del.C. §§1121(33) and 1122. Compare Section VI.

Fifth, Section V.A.4 contains an incomplete internal note related to the individual rights policy. Consistent with the "Third" paragraph above, note that the ICF/MR regulation does not exclude HRC review of drugs approved in a Behavior/Mental Health Support Plan.

Sixth, in Section V., Pars. 3 and 4 are repeated verbatim on pp. 2 and 3.

Seventh, Section V.G. requires each HRC to have at least 5 members. The NCC HRC has not had 5 members in recent memory.

Eighth, Section V.H. and V.P. require the presence of 51% of the HRC membership to constitute a quorum. SCPD recommends establishing a quorum of 1/3 of the members. Otherwise, the current NCC HRC, with 4 members, must have 3 members present. It is common for the HRC to operate with only 2 members.

Ninth, Sections V.D., V.E., and V.N. prohibit disclosure of all information shared within the context of the HRC. The Division Director has historically authorized the DLP representative to include the following caveat in signing the Confidentiality Statement: "Exception: Non-personally identifiable summary information/statistics can be included in DLP reports to the federal government". This permits the DLP to include brief information in its program performance reports to the Administration on Developmental Disabilities and SAMHSA. This authorization should be incorporated into Sections V.D., V.E., and/or V.N.

Tenth, Exhibit C, Par. 6, requires the provider to identify the mechanism "to ensure that the decision-maker...will be periodically advised of progress, problems, etc. relative to the support approach." SCPD does not recall such information being included in plans presented to the NCC HRC. DDDS may wish to review whether such information is solicited and memorialized in standard forms used by the Division.

Thank you for your consideration and please contact SCPD if you have any questions or comments regarding our observations on the proposed policy.

Sincerely,

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

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

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