

ANALYSIS OF STATE CORRECTIVE ACTIONS RELATING TO, OR AS A RESULT OF THE DEATHS

The following are state level actions that were taken in response to or in the aftermath of several of the deaths, along with an analysis of their effectiveness and impact. These actions were reported in correspondence by Ken Nielsen, Esq. of DHHS' Office of Client and Legal Services (OCLS)

1. Establishment of Sentinel Policy and Protocol in 2005 for review of sentinel events (e.g. deaths) by senior DHHS officials in order to draw and apply lessons from the event. Since this is pr a review, it does not include all the fact finding methods of an investigation, nor are determinations regarding culpability made. When this process was implemented, selected joint OCLS and BDS death investigations, begun in 2001, were stopped. The results and the documentation of these Sentinel Reviews are kept confidential. All requests by DRC for Sentinel Reviews have been denied by DHHS, asserting a quality assurance privilege. Therefore the quality or thoroughness of these Sentinel Reviews has not been evaluated. The cessation of actual death investigations at the state level was troubling. Commendably, the recently revised He-M 202 regulations permit the resumption of death investigations by OCLS. Whether resumption has in fact occurred has not been determined.

2. According to Mr. Nielsen's correspondence, new language was added to several sets of regulations, including most notably He-M 506 on staff training, He-M 517 on Covered Medicaid waiver services, and He-M 1001 Community Residence regulations. However an actual examination of the reported changes shows little or no material change, and in one case, an actual weakening of a requirement. For example, one of the changes under He-M 506 was the requirement to train staff on "understanding... the importance of common signs and symptoms of illness." He-M506.05(e)(5)(c). This somewhat cryptic addition is not sufficient given the findings in the investigation and the needs of many individuals served by the system. The timeframe for the training – within 6 months of the client's placement – is extremely late. In CJ and VH deaths, the signs and symptoms occurred within 10 days and 5 weeks respectively.

In He-M 517, which was readopted in 2006 (after the VH death), the Nielsen correspondence indicated that the regulations added the requirement of a "health history." This, in fact, did not represent a change in the regulations.. Under the pre-2006 He-M 517 regulations, under the medical documentation section, the service coordinator was already required to keep the person's "history." The change merely added the adjective "health" to the section. He-M 517.07(b)(1)(2) now reads "health history" instead of "history". It was hardly a needed or material change. The obvious

interpretation under the pre-existing regulations would be health history as the required history was under the medical section of the service coordinator's records.

Under He-M 1001 on Community Residences' regulations some positive changes were made and one problematic one.

- A provision was added for situations when service provision for an individual is transferred from one provider or area agency to another. The regulation lists considerable health and behavioral information that is to be transmitted to the new agency. He-M 1001.08(f)
- Under 1001.08(p) within 5 business days of an individual moving into a community residence or changing residential provider, a service coordinator and licensed nurse must visit the individual in the home to determine if the transition has resulted in adverse changes in the health or behavioral status of the individual. If problems are found, a remediation plan is to be "developed." This is a positive development, though adding the word "implement" to ensure the plan is put into effect would be desirable.
- The He-M 1001's actually weakened an area that was highlighted in the CJ investigation. For emergency certification of an EFC home, a requirement (that existed at the time CJ moved into the residence where he ultimately died) has been removed. The provision, the then He-M 1001.03(c)(e) required the area agency director to determine and certify to DHHS that the home meets standards within 72 hours of the resident moving in. Under current regulations the vendor merely applies to DHHS for certification and has 7 days after the individual is placed to do so.

Provisions regarding behavioral support for challenging clients, a factor in these cases, remained essentially unchanged. With regard to risk assessment and interventions in fire and other areas, there is some additional specificity in the language. However the requirements were already clear in the pre-existing regulations regarding evacuation of individuals within 3 minutes.¹ The requirement of the local fire inspector to ensure that fire and life safety codes are met remains.

3. BDS guidance documents instructed area agencies to collect information and conduct annual reviews on individuals in frail health. The information gathered from reviews is then provided to the BDS staff nurse who in turn conducts her own selected reviews. This seems like a welcomed development, though DRC has not evaluated it for its effectiveness, and several weaknesses do appear. First, from one perspective, the definition of this "medically frail"² group seems so broad that it could arguably include a very high percentage of the approximately 4,000 persons in the DHHS/AA residential day services system. Indeed it was recently learned that in complying with the

¹ The problem in most of these deaths is not lack of requirements, but that the requirements were not followed. He-M 517 and He-M 1001 had and have **numerous** requirements that if they had been followed would have reduced the risks in these deaths and likely have prevented them. As indicated, however, additional and more specific regulations are needed in the He-M 521 family home regulations as well as in the staff training regulations, He-M 506(a). (See Recommendations V(B)(2)(c) & (e) in body of paper.)

² Under these DHHS/BDS guidance documents, individuals in frail health are those who have an acute and/or chronic medical problem that results in an inability to perform their normal activities of daily living or their daily routines, and which requires ongoing monitoring to prevent deterioration.

BDS guidance documents, AAs tended to over-identify individuals in this category. Six hundred (600) individuals were identified as being medically frail. While erring on the side of caution is usually a good thing, when carried to an extreme it can lead to inefficiencies and dilute or weaken services as the system becomes needlessly overwhelmed. The DHHS/BDS nurse acknowledged over-identification was a problem and is working to correct it. Second, from another perspective, the definition may be under inclusive, missing persons who have challenging behavioral issues CJ and ST. These BDS disseminations would not necessarily flag individuals like ST or CJ whose long term and precipitating issues were viewed as primarily behavioral. Indeed ST, whose death occurred well after the guidance documents were issued, was not so identified and thus provided additional attention or monitoring.

4. The He-M 1200 regulations which previously just focused on “Administration of Medication” have recently been broadened during the periodic re-adoption process to encompass provisions on health care coordination for individuals receiving residential services in the DHHS/AA system. Additional measures were also added specifically relating to individuals considered “medically frail,” including a refined definition of “medically frail.” This proposal does demonstrate that DHHS is moving in the right direction, however improvements are still needed in:

- the role and responsibilities of the nurse trainer,³
- the nature and sufficiency of training of the nurse trainer to ensure adequate specialized knowledge in developmental disabilities and health issues,⁴
- DHHS/BDS’s quality assurance role in assuring that the needs of persons with medically frail conditions are being met,⁵ and
- Continued over reliance on the home provider in coordinating care when complicated medical issues are present without a significant upgrade in the qualifications or training of providers.

³ The revised He-M 1200 regulations require the “nurse trainer” to meet with each individual and provider within 30 days of residency. However 30 days appears unduly delayed. Often, as reflected in the CJ death, serious incidents or conditions can and are often more likely to arise early in the residency. The CJ death occurred 10 days into his residency. A far better, if not essential approach, would be to require the nurse trainer to have involvement prior to the residency at least for individuals with significant acute or chronic conditions. The nurse trainer would be able to have input in a timely way on the appropriateness/adequacy of the placement and what supports may be needed. It could also be decided then when the nurse trainer should have her initial with a presumption of no later than 5-10 days after the residency begins. Another shortcoming in the regulations is that they only require a “review” by the nurse trainer. There is no explicit requirement to take action based on the review or when the nurse trainer otherwise receives concerning information from the provider. While arguably most nurse trainers would act as needed, there should be no ambiguity here. The VH case demonstrates the need for a specific requirement.

⁴ The regulations do formalize the role of “nurse trainers,” however the requirements and training seem unduly minimal. The regulations did not follow the recommendation in the VH investigation that all “Nurse Trainers” in the DHHS/AA system have certification from the Developmental Disabilities Nurse Association and that nurses be given the financial and time expenditures necessary to become certified. VH Investigation Report, p. 36 at www.drcnh.org/deaths.html.

⁵ It may not be necessary for the single nurse at BDS to comprehensively check every case given the now more explicit role of the “nurse trainer.” However the need remains for a quality assurance component to assure that the respective personnel on the ground are carrying out their activities properly and the intended beneficiaries are receiving the services they need to address their health condition(s).

