

Testimony of the Office of Protection and Advocacy for Persons with Disabilities
Before the Human Services Committee
February 26, 2008

Presented by: James D. McGaughey
Executive Director

Good morning, and thank you for this opportunity to speak in support of **Raised Bill No. 417, AN ACT CONCERNING THE ESTABLISHMENT OF THE FATALITY REVIEW BOARD**. And, thank you for raising this bill. It is very important to our Office, and, I think it is important for people with disabilities

This bill establishes clear statutory authority for the operation of the Fatality Review Board for Persons with Disabilities, an independent oversight and investigatory body that was originally established pursuant to Executive Order #25, issued in 2002. The Executive Order was issued in response to concerns expressed by families of DDS (formerly called DMR) clients who had died - concerns about the independence and efficacy of DMR's own internal mortality review process; concerns that were echoed by legislators and in the press. The Executive Order created two entities - an Independent Mortality Review Board (IMRB) which is staffed by DDS and operates as a successor to that Department's previous mortality review process, and the Fatality Review Board for Persons with Disabilities (FRB), which is supported by the Office of Protection and Advocacy for Persons with Disabilities. The Order also required DDS to provide information regarding client deaths to the FRB. In 2003, DDS obtained statutory recognition for the IMRB. This Bill would do the same for the FRB, and would expand its membership to include a person with disabilities or a family member and experts in the fields of mental health and forensic pathology.

The concept of a totally independent Fatality Review Board has proven itself. Whereas DDS' IMRB limits the scope of its inquiries to only situations where that agency has direct or oversight responsibilities for the deceased person's health care, the FRB can look into the death of any person who has a disability. The Board currently has only six voting members, all of whom serve without compensation, and only one full time OPA staff investigator permanently assigned to support its operations. Despite its limited size and resources, however, FRB reports have had a significant impact. The first full investigation report we published identified critical deficiencies in nursing home care for a person with mental retardation, and contributed to awareness of problems in that home that ultimately led to its closure. The report also contained recommendations to DDS regarding how to avoid similar tragedies for its clients when they are placed into long term care facilities. Another FRB investigation into the death of an individual who was living relatively independently surfaced major, previously unrecognized structural gaps in health care coordination for DDS clients living in community supported living arrangements. As a direct result, DDS hosted a statewide conference for providers, advocates and its own

administrators to discuss this issue, and has instituted a series of steps to address the problem. A number of the recommendations in the Board's most recent annual report have also been accepted by the Department and, I am pleased to say are being implemented.

In addition to issuing published reports, the FRB has also identified situations warranting referrals to law enforcement and regulatory agencies. For example, very recently the FRB investigated concerns regarding the care and treatment of a woman with intellectual disabilities who had been living in a skilled nursing facility operated by Haven Health Care. The concerns were raised to us by a family member, and our investigation began prior to the revelation's about that organization that were published in the *Hartford Courant*. Our investigation has resulted in referrals to both the Department of Public Health and the State's Attorney, both of which are now conducting their own investigations.

In contrast to the confidential nature of both IMRB activities and abuse/neglect investigations conducted by our Office's Abuse Investigation Division, Fatality Review Board can publish and distribute its reports to policy makers and the press. The fact that FRB reports have received considerable public attention has, in itself, had a salutary effect both within the service system and amongst advocacy groups. While there are good reasons for internal reviews and abuse and neglect investigations to remain confidential, it is also important to have some vehicle for keeping the public informed about realities in service systems, and to give everyone some assurance that oversight is real and truly independent. The FRB does that.

Chaired by the Executive Director of OPA, the FRB is currently comprised of two physicians who have extensive disability and fatality review experience, an experienced forensic investigator with a law enforcement background, a Supervising State's Attorney from the Medicaid Fraud Unit of the Office of the Chief State's Attorney, and a private sector service provider who also happens to be a registered nurse. Our staff tracks and independently screens all deaths reported by DDS, and initiates detailed inquiries into about one - third of the approximately 200 client deaths reported each year. While the FRB has experienced only occasional resistance to its inquiries, being able to cite clear statutory authority for its operations will help answer questions concerning its authority to conduct inquiries and obtain information.

Recognizing the need to devote more resources to FRB activities, OPA has developed plans to restructure our support for FRB activities. Ultimately, we hope to form a new unit that will provide additional staff support for the FRB, and enhance our ability to conduct investigations and publish informative, high quality investigation reports. Establishing the FRB in statute will clarify the legal authority for the FRB's current operations, and assure that its important work will continue.

Thank you again for raising this bill. I urge you to support it. If there are any questions, I will try to answer them.