

Executive Summary

**Connecticut's System for Reviewing the Deaths of Individuals with Intellectual Disabilities;
Lessons Learned from 10 Years of Mortality Reviews and Investigations**

STATE OF CONNECTICUT

OFFICE OF PROTECTION AND ADVOCACY FOR
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Introduction

Fatality Review: How does it work and why is it important?

Questions of trust, blame, respect, confidentiality and fear of consequences and/or liability surround all mortality review processes including those affecting people with intellectual and developmental disabilities. The stakes are high for everyone: for individual human beings who are trying to chart their own courses through life but who may depend, to varying degrees, on the competence and commitment of care givers to help them navigate through the world's complexities; for families seeking answers to agonizing questions; for providers and practitioners whose reputations and ability to continue to practice their professions are on the line; and for leaders in health and human service systems who are trying to implement policies that genuinely respect personal autonomy and individual choices on the one hand, yet establish reasonable safeguards and accountability mechanisms on the other.

Ten years ago, in response to questions about the levels of accountability and trustworthiness with which its developmental services system was monitoring client deaths, Connecticut created a mortality review process which is characterized by independent checks and balances. In contrast to previous practice, the current system has both internal and external components. It assures that the death of each individual who receives even minimum levels of service through the developmental services system is reviewed, that suspected abuse and neglect are independently investigated, and that trends and systemic problems are identified so they can be addressed. After ten years of operation, a much more complete picture of the mortality experience of people with Intellectual Disability has emerged and a number of important issues have been identified. Many of those issues have been addressed while others still require action.

Also emerging is a more sophisticated understanding of what the more persistent "problems" represent. When there has been an error or significant omission which has led to an individual's death – something that never should have happened and never should be allowed to happen again – it is tempting to respond by imposing new procedural requirements, or by mandating universal training on a particular topic, or by adding additional layers of oversight. Sometimes such responses are warranted and actually helpful. But, sometimes, the 'problem' is not so easily isolated and addressed; sometimes it is a symptom of an underlying issue, like the slow starvation of the State's chronically under-funded network of community service providers over the past fifteen years; or the naïve, yet widespread assumption operating within the culture of the developmental services system that it can do little to affect outcomes once its clients become "patients" in healthcare environments. Sometimes, too, the underlying problem can be best understood as one of misplaced administrative emphasis – too much reliance on regulatory requirements, bureaucratic detail and the myth of organizational perfectibility, and too little investment in cultivating competence and renewing commitment within the "human infrastructure" that is the blood and bones of any human service. Just as Gandhi warned against "systems so perfect that nobody needs to be good", one of the most

significant lessons fatality review teaches involves the critical importance of good values and a sense of shared responsibility on the part of people at all levels of the service system.

The good news is that Connecticut now has a comprehensive mortality review system, and it is clear that most – the vast majority – of deaths reviewed raise no questions about the quality of services or care. In fact, the records reviewed by the Fatality Review Board indicate that many of the individuals who died were genuinely respected, well supported, very much cared about by others, and that a number of those who had terminal conditions were able to pass away in their homes, supported to the end with dignity, respect and affection. At the end of our lives, we should all be so fortunate. Clearly there are many competent and committed caregivers supporting people with Intellectual Disabilities. But, an honest look requires that we acknowledge that too many things still go wrong, and that there are important lessons to learn by vigorously reviewing those cases. We owe it to those whose deaths were untimely to continue to pursue those lessons. In the end, a commitment to continual learning – to relentlessly pursuing an accurate understanding of what happened in each case - what worked and what didn't, what contributed and what interfered, what needs to change – may be the most important way we can honor those people.

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Ten years ago, Connecticut began a process of systematically reviewing the deaths of State residents with Intellectual and Developmental Disabilities (ID/DD). That process provides for independent investigations into those deaths that raise the specter of abuse or neglect, and structured review and inquiry to determine whether there were lessons that could be learned from any of the deaths – lessons that could improve quality of care and prevent problems from recurring. Over a period of several years, through a combination of Executive Orders and legislative mandates, three inter-related mechanisms were put in place – each with a distinct role and identity. They are: 1) the Fatality Review Board for Persons with Disabilities (FRB), supported by the Office of Protection and Advocacy for Persons with Disabilities; 2) the Independent Mortality Review Board (IMRB), supported by the Department of Developmental Services; and 3) a statutory requirement that OPA's Abuse Investigation Division (OPA/AID) directly investigate the deaths of persons with ID/DD in which abuse or neglect is suspected of playing a role. While all three entities share information, each performs its assigned function independently. In essence, the system is one of checks and balances which, taken together, reduce the likelihood that issues will be missed or ignored, significantly improves accountability, and capitalizes on the different perspectives that each entity has to offer.

This report summarizes the experience of the Fatality Review Board for Persons with Disabilities over the ten years that it has operated. Chaired by the Executive Director of OPA, and supported by an OPA staff investigator, the FRB has five members drawn from medical, human service, law enforcement and education professions. Of the three components that comprise Connecticut's mortality review system, the FRB has the broadest jurisdiction, concerning itself with the death of any person with ID/DD, irrespective

of where the person lived or whether he or she received State-funded services. In the process of fulfilling its mandate, the FRB also reviews the results of investigations conducted by OPA/AID; determinations reached by the IMRB; and, under certain circumstances, the results of inquiries conducted by the Department of Public Health (DPH). Unlike the other components of the system, the FRB is also expected to issue periodic reports on its operations to policy makers and the public.

Although this report has been prepared as a ten year retrospective, the case data it cites reflects the seven year period stretching from January 1, 2004 through December 31, 2010. (2004 was the first full year for which data on abuse/neglect investigations is available, and, because a number of investigations into deaths occurring in 2011 and 2012 are still open, data from those years is incomplete.) During the reporting period:

- A total of 1,361 deaths were reported by DDS (formerly DMR) to OPA and tracked by the FRB.
- 82 of those deaths involved suspected abuse or neglect. OPA/AID initiated investigations into all but one of those cases and has, to date, completed 79 of them.
- In 55 (or 70%) of those completed investigations, an allegation of abuse or neglect was substantiated, although in 5 cases there was insufficient evidence to determine that the neglect that was found to have occurred had contributed to the person's death.
- 40 of those substantiated allegations (2.9% of total deaths reported) arose in programs operated or funded by DDS.
- An additional 25 reports of suspected abuse and neglect - related deaths involved discrete questions about the care and treatment of individuals in healthcare facilities or by medical professionals. Those cases were investigated by the Department of Public Health, whose findings were reviewed by the FRB.
- In addition to the cases investigated by OPA/AID and DPH, the FRB conducted in-depth reviews and/or investigations into 445 of the 1,361 deaths that occurred during the reporting period (33% of all reported deaths).

The vast majority of the 1,361 client deaths reported to OPA during the reporting period raised no concerns about quality of care. In fact, many of the reports reviewed by the OPA staff and the FRB reflected considerable competence and commitment on the part of care-givers and service providing organizations. However, some systemic issues were identified both in the non-abuse/neglect cases reviewed by the FRB, where questions of quality, best practice and previously un-recognized risks are likely to surface; and in the course of abuse/neglect investigations which have sometimes found evidence of a lack of caregiver awareness or responsiveness to known client needs, the absence of clear protocols for communications and decision-making, or of unmet staff training needs. Those systemic issues and the FRB recommendations regarding them include:

- Nursing home placement is often problematic and should be avoided if possible. A significant number of cases reviewed by the FRB raised questions about both the quality of care individuals

with intellectual disabilities received in nursing homes, and the reasons why they had been admitted in the first place. One of the FRB's first investigation reports involved a man who lived in a group home, but was not able to immediately return there following a hospital stay due to ambulation difficulties. Staff from his group home faithfully visited him and tried to inform the nursing home staff regarding problems they were observing with his care. The information was ignored and his death was determined to have been caused by neglect. Another DDS client was also placed "temporarily" for rehabilitation into a nursing home following hospitalization. Although her group home staff had prepared a detailed list of her health and dietary concerns – including a clear warning that she needed to have her food pureed – on the afternoon she was admitted to the nursing home she became upset and demanding of attention. Ignoring the important information provided by the group home, nurses at the facility told the staff to make her a peanut butter sandwich. She choked and died. The FRB recommended that, to the maximum extent possible, DDS avoid placing people with ID/DD into nursing homes, but that when doing so was necessary, that they be placed into "preferred facilities" – homes with better track records for serving people with ID/DD, and for keeping DDS informed as to their status. Until recently it was assumed there was little DDS could do to address these recommendations, as many temporary nursing home placements were arranged by hospital discharge planners. However, DDS Commissioner Terry Macy has indicated that he hopes to move the DDS system in a direction that will enable people to "age in place" rather than have to enter long term care facilities, and has begun the process by ordering that community providers offering placement to residents of Southbury Training School make commitments to support people in their homes.

- Competent healthcare coordination and assertive advocacy are critically important to prevent people from "falling through the cracks" of our complex, increasingly fragmented healthcare delivery system. This issue appears across all healthcare environments (hospitals, nursing homes, clinics, physicians' offices, etc.) and in the various settings where people with developmental disabilities live: campus facilities, publically and privately operated community living arrangements (group homes) and supported living arrangements. Even people who live on their own with minimal supports, or who live with family members can "fall through the cracks" in our ever-more complex, fragmented healthcare delivery system. In a number of cases the FRB and AID found problems involving unclear expectations between direct care staff and agency nurses; in others the problems involved incomplete or inaccurate communication between agency personnel and healthcare practitioners. In still other cases, healthcare providers focused attention on one aspect of an individual's health status, but failed to consider (or did not know about) important background information regarding the individual's history or diagnoses. (As our healthcare system has grown increasingly focused on treatment specialties, this has become an increasing problem for everyone.) The FRB has consistently recommended that steps be taken to clarify the roles and responsibilities of agency nurses and "on-call" nursing services. For people known to have chronic health problems, it has also consistently recommended that knowledgeable coordinators be designated to assure that vital information is communicated amongst practitioners, and to advocate for good care and treatment. DDS has responded by taking some steps to clarify nursing roles, and by amending its Home and Community Based Medicaid Waiver to recognize healthcare coordination as a discrete, reimbursable service. More recently, the FRB has undertaken a training initiative, along with the University Center for Excellence in Developmental Disabilities at the UCONN Health Center, which is designed to inform and empower residential staff, case managers, family members and caregivers so they can more effectively advocate in healthcare environments.

- Preventing fatalities from choking, drowning, falls and burns requires awareness, constant vigilance, effective communication strategies, and attention to both the physical environment and the adequacy of staffing. Investigating allegations of neglect in connection with accidental deaths is, necessarily, a fact-driven, one-case-at-a-time proposition. Nonetheless, OPA/AID and the FRB identified a number of common themes. Among these are: failures to formalize and/or follow client-specific food preparation and feeding guidelines for individuals who are known to be prone to choking while eating; failure to develop and communicate the need to provide close support to individuals who are known to be unsteady while ambulating; failure to follow individual water-safety plans; failure to check water temperature prior to placing individuals into bathtubs and showers. In response to these findings and recommendations, DDS implemented a major drive to provide training and develop uniform policies concerning dysphagia. Anti-scald devices are now required for all licensed residential programs, and water safety policies were revised and incorporated into new employee training.