



State of Connecticut  
Department of Developmental Services

DDS

Dannel P. Malloy  
Governor

Terrence W. Macy, Ph.D.  
Commissioner

Joseph W. Drexler, Esq.  
Deputy Commissioner

March 20, 2013

MEMORANDUM

TO: Individuals, Families and Community of Providers

FROM: Commissioner Terrence W. Macy, Ph.D.

A handwritten signature in cursive script that reads "Terrence W. Macy, Ph.D.".

SUBJECT: Hartford Courant Series

Recently, the Hartford Courant ran a series of stories about untimely deaths of individuals with intellectual disability. The series gives a face to the statistics that were reported by the Connecticut Office of Protection and Advocacy (OPA) some months ago. Both the OPA report and this more public account in the news rightfully highlight the need for continuous improvements to our systems of support. While one preventable death is too many, it is important to note that Connecticut has systems in place to review deaths and identify the need for system improvements.

Over the years, DDS and our private provider partners have initiated many improvements to address issues such as scalding, food consistency, and falls. There are many thousands of direct care employees in the public and private sector who do a great job everyday providing supports in a safe, attentive manner. Their work is appreciated by people who receive services and their families, providers and DDS. Unfortunately, we have found that the individuals we support do not always universally experience the same respect and safeguards afforded to other segments of our society.

What the Hartford Courant series did not report on is the many system improvements that have been made over the years that have provided safeguards for persons with disabilities, including some that few other states have yet to develop. A multi-level mortality review process was established to examine all deaths and issues related to cause and prevention. All deaths receive a medical desk review by nurse investigators and are reviewed by a regional mortality review committee. The facts and circumstances of many of those deaths are also reviewed by an Independent Mortality Review Board (IMRB). Connecticut law requires that DDS review the death of anyone for whom it has direct or oversight responsibility for medical care. The review must cover the events, overall care, quality of life issues, and medical care preceding the death to ensure that a vigorous and objective evaluation and review of the circumstances surrounding untimely deaths take place. DDS is required to report to OPA within 24 hours whenever it determines that there is reasonable cause to suspect or believe that abuse or neglect may have contributed to a consumer's death. That reporting requirement applies to anyone for whom

DDS has direct or oversight responsibility for medical care, and who was 18 years of age or older at the time he or she died. OPA is required to directly conduct investigations into those deaths. The Abuse and Neglect Registry provides a process to review abuse and neglect cases as reported by multiple sources and evaluate whether persons terminated for substantiated abuse or neglect should be placed on a statewide registry that prohibits them from working in the field. This system assures that the death of each person receiving DDS services is reviewed, that questions about both individual circumstances and systemic issues are addressed, and that allegations of abuse and neglect are independently investigated.

In addition to important system changes described above, other steps have been taken over the last several months. DDS is focused on sharing information on prevention strategies with public and private providers. A link on the front page of DDS's website shares contact information for reporting suspected abuse and neglect and provides a resource for self advocates. Prevention has been a constant subject of discussion at many recent meetings with public employees and private providers. The department has also revised the way abuse and neglect registry cases are reviewed making the process more efficient and timely.

Going forward, there will be a continued focus on prevention. DDS plans to meet with other human service partners including the Department of Public Health and the Connecticut Office of Protection and Advocacy to examine how together we can better monitor the care of persons with intellectual disability in nursing facilities. DDS has prohibited the permanent transfer of anyone from Southbury Training School to a nursing home. DDS staff is developing a policy to clarify the department's commitment to end of life planning in existing residential settings in lieu of nursing home placements. As has been expressed by DDS on several occasions, nursing homes should not be the setting of choice except in very limited circumstances. It is critical that we work with as many partners as possible to ensure that the best medical care is always provided to those we support. We will continue to work with the Ombudsperson for Developmental Services to be vigilant of nursing facilities that develop any pattern of inadequate care. We will also be performing a more systemic review of mortality cases to determine if there are larger patterns of neglect that require new kinds of review or intervention. Looking at the longer term, DDS will continue to seek opportunities for building partnerships with our medical community to better ensure responsive medical care to the individuals we support.

The Department of Developmental Services recently revised its Mission and Vision. These documents provide clear and certain perspective on the valued role persons with intellectual disability play in our society. We will continue to share and promote our vision while encouraging more inclusive and supportive communities. Self advocates and their families play the largest role in shaping a future that ensures persons with disabilities are valued and that health care and other support systems are responsive to their needs.

I hope that the publicity around these deaths will remind all of us of the importance of the work that we do and the need to continue to strive to have a continuously improving system of supports which allows each person to safely pursue the life of their choosing.