A Brief History of Mortality Analysis in Virginia Following the Settlement Agreement with the DOJ

This brief history of mortality analysis in the Commonwealth of Virginia to track the well-being of those who are at extraordinary risk of death from conditions associated with their Intellectual and Developmental Disabilities (I/DD). It describes what data were made available, some issues with those data, my analyses of these raw data, and outstanding issues with performing and willingness to perform such analysis.

Since mortality is a clearly defined quantity, it is foundational to tracking the risks and performance of a system of supports. Mortality is not a substitute for a host of other performance measures, but the willingness to analyze and report mortality is a good indicator of how publicly accountable the administrators of a system of supports are willing to hold themselves. It is also a primary indicator of the sustained need for extraordinary supports for those of exceptional vulnerability as a result of their I/DD. This brief history reports on my independent attempts to perform mortality analyses that those administering the system of supports were not willing to perform themselves and to describe the ongoing controversies surrounding what an adequate analysis of mortality should consider.

Background and Framing

In 2012, the Department of Justice (DOJ) signed a Settlement Agreement with the Commonwealth of Virginia. That Agreement had provisions to review all deaths and serious harm that befell anyone leaving one of Virginia's five Training Centers (TC) that were open at that time. Note that a TC is just another name for an ICF/IID. Although the Agreement only required Virginia to provide a placement in the community for anyone who wished to leave a Center, the Department of Behavioral Health and Developmental Services (DBHDS) chose to implement a plan to close all but one Center. By the Fiscal Year 2017, the statewide census among the Centers still open was down to only 25 percent of the initial combined census.

Several organizations review and analyze mortality of those discharged from TCs. First, the DBHDS established a Mortality Review Committee (MRC) that in addition to investigating the root causes of death is to report on trends and patterns of mortality. The court also established an Independent Reviewer to analyze Virginia's conformance with the Settlement Agreement to include reviews of mortality and analyses of patterns and trends. Finally, the DOJ brought in their own analysts to review mortality, assess the adequacy of what was being done, and determine whether excess harm might be taking place.

Unfortunately, none of these three government entities performed and publicly released a competent analysis comparing mortality among those discharged to the community to those remaining in Centers. This brief history introduces my independent comparative analyses; see the attachments.

Mortality by Training Centers (FY2011 to FY2014)

By the end of FY2014, enough time had passed to look for statistically significant increases in mortality among those who had left the Centers if that increase was comparable to the one reported by Strauss, Kastner, and Shavelle in 1998 for California. Also by 2014, advocates for those in Centers had gained support and both houses of Virginia's Generally Assembly to unanimously pass Senate Bill 627 (SB627) requiring the DBHDS to form a Task Force to determine how many residents wished to stay in Centers and how to accommodate them. In support of their position of continued closures, DBHDS submitted a deeply flawed

analysis of comparative mortality purporting to show that Centers had higher mortality rates. Since that analysis included the raw mortality data by year and Center, I was able to reanalyze these data appropriately. About a year later, I obtained the census data for each Centers for those first 3 years.

The first attachment shows the results of this updated and more accurate analysis.[1] An essential feature was the comparison of Central Virginia Training Center (CVTC) to all of the others. The CVTC had a Skilled Nursing Facility (NSF) for those with very serious health complications which might explain its exceptionally higher mortality rate than any of the other centers. So high in fact that even without knowing CVTC's exceptional status, it would have stood out as dissimilar from all the other Centers. Using all of the Centers other than CVTC as a baseline for comparison, the raw mortality rate among those leaving was 91% higher than those remaining in Centers. By dropping even those few CVTC residents who transitioned to the community, the odds were still 22:1 against the Centers having higher mortality rate than among the people who left for the community. In this reanalysis, the estimate of excess mortality rate in the community remained virtually unchanged at 88%. The full analysis addresses a few other points including the statistically significant increase of mortality among those going into Nursing Facilities as one of the first of the Centers was closed.

In October 2015 partially in response to my analyses, the Independent Reviewer included a statement in his report to the court: "Qualified staff for both the Mortality Review Committee and the Department of Justice independently determined that the mortality rates have not been higher for individuals who were discharged from the Training Centers under the Settlement Agreement compared with those who continued to reside in the Training Centers." However, neither Independent Reviewer nor the DBHDS publicly released their data or their analyses to support this claim. In conversations with DOJ and DBHDS, they shared with me that they saw no reason to exclude CVTC from the TC baseline as exceptional, hence saw no statistically significant increase in mortality among those who had transitioned. They did not volunteer any reason for accepting CVTC's exceptionally higher mortality rate as comparable to other Centers or look into possible reasons for this difference.

Overall Mortality (FY2011 to FY 2017)

The Director of Quality Management at DBHDS was gracious enough to work with me in reviewing mortality trends and patterns for the period up thru FY2017. Virginia continued to struggle with improving data quality by trying to untangle minor inconsistencies in the census at the centers and more seriously to get access to the information to evaluate all deaths among those with I/DD. A variety of privacy protections enabled some families and providers to withhold information or just not revisit a painful experience even though the mortality review process was not looking for criminal prosecutions.

After a few false starts – DBHDS engaged two different analysts only to later to have them leave – a third analyst produced a report again showing no increase in mortality for those leaving TCs. My review of this work revealed glaring inconsistencies and errors in reporting the TC census data across the years.[2] Working with the total number of deaths per year in all

[1] Mortality Rates, Good Data and Objective Analysis of Data Are Key Measures of a Good Quality Management System, Robert Anthony, May 20, 2016.

[2] The most obvious of these is the total of all those in centers plus those who left or died did not sum to the initial census. Worse, it fluctuated year to year to a number greater then less than the initial census. While some individuals left the state, and centers were not supposed to take additional residents, there was no explanation for this discrepancy other than a serious misunderstanding on the part of the new analyst.

settings, my analysis in the second attachment compares the observed pattern of deaths with that expected if there had been a constant mortality rate over the six years from the beginning of FY2011 to end of FY2017.[3] Comparing the initial three years with the subsequent three years of the entire period revealed that the mortality rate in the latter period was 71% higher than the former. This is a highly statistically significant result in that the number of deaths had increased by 52% in the second period, while mortality reduced the number of people being exposed. Moreover, the year FY2016 had such a large excess of deaths over expectation, that it stood out as anomalous no matter what year that discrepancy had occurred.

Soon after completing this work, the third analyst also departed, DBHDS reorganized so that Quality Management was under a different person, and my working relationship on this effort ended. Yet once again, the DOJ independently engaged an analyst to review the mortality data from Virginia. She commented that without controlling for the aging and other factors among the original cohort of TC residents, she did not trust my results based on raw mortality rates. Since the full records on ages had been archived and DOJ saw little value in performing comparative analysis. Instead, she analyzed the leading causes of death and later DOJ focused on these in future reporting. I subsequently reviewed those age distribution data I had, and aging did not seem capable of explaining the mortality rate increase.

Mortality Reporting by DBHDS

The DBHDS has publicly released two Annual Mortality Reports, one for SFY2016 and SFY2015 and another for SFY2017.[4] Neither report gave even the raw mortality rate for those who have left the Centers nor for those remaining. Nonetheless, they do report the average tenure in the community and age at death suggesting DBHDS has access to the information necessary to report raw mortality rates as is done for those on waiver. Instead, they state, "Due to the shifting population out of training centers, mortality rates for individuals that died in a training center are subject to large fluctuations. Such a rate would be considered unstable, and is therefore not included in this report" (AMR SFY2-17, page 7).

Both reports cover all mortality among everyone receiving Medicaid support for I/DD. This is good in that it is inclusive, but it also threatens to obscure the exceptionally vulnerable minority in their midst. Supporting that minority is very expensive making them visible targets for cost cutting. Without the countervailing reporting of extreme their need, there is a risk of eroding support hidden by the invisibility of ever higher mortality.

One indicator of this extreme need is the raw mortality rate reported for those in the highest levels of waiver support for their medical condition. They have mortality rates 6 times greater than those in the normal population. By contrast, those in the other levels of waiver support have mortality rates less than that for the normal population (8.2 per 1,000 person years). This minority with medical complications is only 9.6 percent of all those on waiver.

The AMRs reported on leading causes of death that were for the most part well known beforehand. For example, bed sores and subsequent deaths from sepsis never happened in the better run TCs, but are a problem in the community. Rates of choking and bowel obstruction are also preventable and seldom happened in TCs, yet these are major contributors to preventable death in the community.

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[3] Statistical Analysis of Training Center Downsizing and Closures: Opportunities and Necessities, Robert Anthony, August 8, 2018.

[4] The dates of release are for the year after the period being reviewed, so the DBHDS reports are AMR SFY2017 and AMR SFY2018,

The Situation in 2020

The DOJ and court oversight are coming to an end as both parties negotiate a set of about 300 conditions that Virginia must meet. Many of those address Quality Management and are a big step forward from previous practice. One can be thankful that Virginia signed up for so many promises in the original Settlement Agreement. However, Virginia is only held responsible to report publicly the raw numbers of deaths and causes of death, but not any results of analyses of patterns and trends.

If the past experience is any basis for future expectations, Virginia will continue to report overall tabulations of deaths and some raw mortality rates but keep any analyses of patterns and trends within management circles. Mortality reporting focuses on causes of death to manage the preventable causes more closely, which could be useful. But without the necessary data and bases for analysis of those with extraordinary need, advocates cannot bring any problems or creeping decline in standards of care to the attention of legislators. Moreover, with the Managed Care Organizations in charge of approving supports, the focus is likely to be on cost savings by requiring ever more justification for expenses. Without having a public accountability for the health consequences or recognizing possibly better systems of practice that could save both lives and money, those with extraordinary needs unnecessarily be placed at great risk.

Attachments

1. Mortality Rates, Good Data and Objective Analysis of Data Are Key Measures of a Good Quality Management System, Robert Anthony, May 20, 2016.
2. Statistical Analysis of Training Center Downsizing and Closures: Opportunities and Necessities, Robert Anthony, August 8, 2018.