

Mortality Rates, Good Data and Objective Analysis of Data Are Key Measures of a Good Quality Management System

Quality Management addresses aspects of the system of supports for those with intellectual and developmental disabilities (I/DD) that are essential to health, safety, and well being. These must not fail. Objective measures supported by good data and competent analyses can reveal how the system is working. Unfortunately, doing these analyses in-house, without providing the information necessary for third parties to assess the analyses, provides an incentive for the regulatory agency [the Department of Behavior Health and Developmental Services (DBHDS) in Virginia] not to disclose, or downplay, negative results, as such results would reflect poorly on those charged with providing those supports. Since DBHDS is responsible for both managing and evaluating performance, there is an inherent conflict of interest that could bias their conclusions in the absence of transparency, i.e., the public release of the underlying data and associated analyses. Such a release of information would also assure the interested public that the right questions are being asked for Quality Management.

Mortality rates are a primary measure of performance for the supports assuring health and safety. These rates are based primarily on simple counting of objective events and offer a useful test case for public accountability of DBHDS data collection, reporting, analysis, and interpretation of the implications for overall health and safety. Of special concern are the outcomes for those most vulnerable to harm as a result of their I/DD and associated medical or behavioral complications. The ongoing downsizing and closure of Training Centers offers a natural experiment that could reveal whether community supports do in fact provide “comparable care,” as promised by SB627.

The Independent Reviewer for the court in his December 6, 2016, report states that, “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 this report nor the DBHDS published the data and analysis to support this claim.

Without an explanation of how these qualified staff reached this conclusion, the informed public and especially this author are confused concerning the interpretation of the mortality data that could lead to such a conclusion, since data thru FY14 published in conjunction with the SB627 Work Group would lead to a quite different conclusion, that is, *those who left centers suffered nearly double the mortality rate of those who remained.*

This author’s analysis, which is attached, presents all the data released by DBHDS thru June 2014 as well as the author’s assumptions and methodology. Absent the disclosure by the DBHDS of any additional information or analysis, this author can only guess at the reasons for such divergent conclusions. But reviewing the attached analyses should illustrate to the reader how confusion might arise and will remain until there is a more open sharing of data, analyses, and results. This author analyzed five comparative interpretations and obtained the following results:

1. Comparing the mortality rates at each center relative to that at all other centers revealed that Central Virginia Training Center had a mortality rate that stood out at

double that of the other centers taken together – an event with 908:1 odds against. Note that unlike the other centers, CVTC has a Skilled Nursing Facility.

2. Comparing all those who moved to the community with those at all centers except CVTC implied that the mortality rate was 91 percent higher in the community than in the centers. Since those who were first to leave any center were generally healthier and at lower risk than those who remained, except for those leaving Southside Virginia Training Center just before its closure, the odds against this result being a random event are 38:1.
3. Comparing mortality rates without either CVTC residents or those having left CVTC still implies an excess mortality rate of 88 percent for the community relative to the other centers, with odds against this being a random event of 22:1.
4. Comparing only those who left centers *for a community ICF/IID or waiver slot* with those who remained at centers *or went into Nursing Facility or State Facility* implied that those in “community” placements had a mortality rate only 29 percent higher, with odds against this happening at random of only 3:1, a truly insignificant difference. Yet SVTC was forced to close, and 4 of the 5 deaths at NFs were among those from SVTC, a clustering with 20:1 odds against. Charging NF deaths to centers is unwarranted since a community-based system would use NFs for palliative care.
5. Finally ignoring the higher mortality at CVTC and comparing mortality rates for *all centers* with *all those leaving centers* implies a 31 percent higher rate in the community but insignificant odds of only 4:1 against being a random event.

During a period of transition, one can expect some elevated mortality risk, and detailed examination of each case has revealed some of the underlying reasons for these deaths. Nonetheless, an increase risk of 88 to 91 percent seems excessive even for a transition. Surely the results of this analysis as well as those of DBHDS warrant a thorough evaluation and public explanation of both the data quality and the analysis supporting any findings. The Independent Reviewer has repeatedly pointed out the deficiencies in the process DBHDS uses to review deaths among those who moved to the community. It is critical that DBHDS institute evidence based methods in its Quality Management and especially get to the root causes of deaths among those moving to the community before the ongoing transition puts more lives in harm’s way. Comparative mortality analysis during the transition process offers a rare opportunity to highlight the vulnerability of those with complex conditions and the requirements for adequate supports in various settings.

For the good of all persons with I/DD, the author urges the DBHDS to share the full results of its analysis. Doing so should not violate HIPPA in that the data are quite aggregated. The interpretation of these data should be informative to all since the data revealed so far yield a result quite different from that stated by the Independent Reviewer.

Two questions warrant urgent attention. Why is the risk of mortality so much greater at CVTC than at other centers? If CVTC were to close, might its residents experience even greater risks in the community than those who have left other centers? Other questions address the efficacy of Quality Management. How can Virginia identify those in the community who have up to five times the risk of the typical community resident and report on their outcomes separately? How soon might QM data trends or patterns reveal statistically significance exceptional risks, and what harm might occur beforehand?

A Comparative Analysis of Mortality Rates: Those Leaving Virginia's Training Centers vs. Those Remaining

Background

A prior analysis by this author was presented to the SB627 Work Group and has been posted on the DBHDS website, but that analysis had to infer the number of residents discharged to the community from each center by taking the difference between the initial census of the center and subtracting both those who remained and those who died. A subsequent analysis benefited from a tabulation of those leaving each center for a waiver placement, a Nursing Facility or State Facility, as well as those returning to a center. These new data clarified the sequencing of moves and provided a consistency check. However, its discussion of data adjustments and inconsistencies was excessively complicated, and it did not consider as many comparative cases as do the analyses presented here. For example, one new case interprets the mortality rate in the community as covering only those on waiver or in a community Intermediate Care Facility for Individuals with Intellectual Disabilities. This case also includes arguments against such a narrow interpretation.

These analyses continue to adopt the academic threshold for statistical significance of 5 percent confidence limits or 19:1 odds against although this threshold is a bit arbitrary and requires years of data accumulation before even very serious problems, such as a near doubling of mortality rate would emerge as “statistically significant.”

Since 2 more years have passed after these data were assembled, a much more statistically significant comparison would now be possible, one that might clarify some of the reasons for the excess mortality reported here.

Analysis and Findings

Each of the five new analyses compares two mortality rates. Those rates are themselves ratios of deaths that occurred over a 2-year 9-month period divided by person-years of exposure over the same period. Rates are reported in units of number of deaths per 1,000 person-years of exposure.

Because the comparison of these ratios is a test of the consistency of the proportionality among four numbers, Fisher's Exact Test for a 2x2 contingency table is an ideal method for calculating the probability of observing those four numbers at random if the underlying populations were in fact proportional. Odds rounded to the nearest integer are easier to grasp than the more abstract probabilities.

One supplemental analysis helps explain how best to characterize community versus center-based settings when making comparisons of mortality rates. It estimates the small chance of observing 4 of 5 deaths under palliative care at NFs to occur among those discharged from one center, SVTC prior to its closing.

To be concise and facilitate easy comparison across all five analyses, Table 1 summarizes these results in a consistent format. After stating the hypothesis to be tested, each analysis tabulates the deaths, person-years of exposure, mortality rates, ratio of mortality rates, as well as the probability and odds against seeing this pattern of deaths and

exposures at random. Large odds against relative to 1 represent a *rejection of the stated null hypothesis stated in Table 1.*

Table 1. Testing Several Hypotheses Based on 2 x 2 Tables and Fisher's Exact Test

Hypothesis 1: CVTC has the same mortality rate as all of the other centers.		Deaths	Person-Years	Mortality per 1,000	Ratio of Rates
	CVTC	41	887	46.2	2.24
	Other Centers	30	1,454	20.6	
				Prob.	Odds vs. 1
Fisher's Exact Test for a 2x2 table		Two sided test		0.0011	908
		One sided test		0.0007	1,428

Hypothesis 2: Those remaining in centers other than CVTC have higher mortality than all those moving to the community.		Deaths	Person-Years	Mortality per 1,000	Ratio of Rates
	All centers but CVTC	30	1,454	20.6	1.91
	From all centers	18	457	39.4	
				Prob.	Odds vs. 1
Fisher's Exact Test for a 2x2 table		Two sided test		0.0389	25
		One sided test		0.0254	38

Hypothesis 3: Those remaining in centers other than CVTC have a higher mortality rate than those moving to the community from centers other than CVTC.		Deaths	Person-Years	Mortality per 1,000	Ratio of Rates
	All centers but CVTC	30	1,454	20.6	1.88
	From all centers but CVTC	14	361	38.8	
				Prob.	Odds vs. 1
Fisher's Exact Test for a 2x2 table		Two sided test		0.0566	17
		One sided test		0.0426	22

Hypothesis 4: Those remaining in centers other than CVTC have higher mortality than all those moving to waiver or community ICF/IDD placements.		Deaths	Person-Years	Mortality per 1,000	Ratio of Rates
	All centers but CVTC	35	1,484	23.6	1.29
	From all centers to Waivers or ICFs	13	427	30.5	
				Prob.	Odds vs. 1
Fisher's Exact Test for a 2x2 table		Two sided test		0.4829	1
		One sided test		0.2673	3

NF and Other Facilities transfers 12 in FY12 and 8 in FY13 =30.5 person-years.

Rationale for including CVTC transfers to the community: None of those leaving CVTC went to NF or SFs.

Hypothesis 5: In aggregate, those who left the centers are better off than those who stayed, all centers combined.		Deaths	Person-Years	Mortality per 1,000	Ratio of Rates
	All centers	71	2,340	30.3	1.31
	All who left centers	18	454	39.6	
				Prob.	Odds vs. 1
Fisher's Exact Test for a 2x2 table		Two sided test		0.3095	2
		One sided test		0.1945	4

Discussion of the Five Comparisons

1. Comparison of CVTC to Other Centers

The Central Virginia Training Center has a large Skilled Nursing Facility unlike all other centers in Virginia. The SNF serves residents whose complex conditions place them at a much greater risk of mortality. As expected, the mortality rate among CVTC residents is the highest among all of the five centers and is 46.2 compared to 20.6 for the average of the other centers. The odds against such a large discrepancy are 908:1. Even if one were to consider that CVTC is only one among five centers, the odds of $908/5 = 182:1$ would still be against its being typical relative to the others.

2. Comparison of Centers Other than CVTC with the Community

Although CVTC itself has an elevated mortality rate, the rate among those who moved out of CVTC into the community is comparable to that for those who moved out of other centers. Only those going to the community from SWVTC had a lower rate, of zero deaths. But there, the small number of person-years in the community means that the number of expected deaths was so small that odds against having no deaths are only 9:1. Therefore, the most revealing and representative comparison between the mortality rate at centers and that in the community would be the aggregate of those at centers other than CVTC and all those who moved out of any center.

The hypothesis that the difference in the mortality rate of 20.6 for the centers and that of 39.4 for those who moved out would happen at random has odds against of 38:1. Since one would expect that *mortality should be higher among those remaining in the centers* as DBHDS first moved out those with the least complicated conditions, a one-sided Fisher's Exact Test is appropriate as just the opposite to the expected result occurred.

3. Comparison Entirely Excluding CVTC

If there is any doubt whether those leaving CVTC were in fact similar to those leaving the other centers, a comparison of mortality rates for all residents of other centers, 20.6, with those leaving those other centers, 38.8, also rejects the hypothesis that such a difference could arise by chance. Here, the odds against comparable rates are 22:1.

4. Comparison of Waiver and Community ICF/IID with All Others Settings

Suppose one considers those going into the community to consist only of those accepting a waiver or a community ICF/IID placement. This means that those going into Nursing Facilities or State Facilities are included with centers as institutionally based settings.

To represent this hypothesis using available data, 5 deaths at NFs would be combined with those at centers while 5 would be removed from community deaths. Similarly, the 30.5 person-years for those residing in NFs or SFs would be added to the center totals and removed from the "community" total.

With this very restricted definition of "community," the community mortality rate becomes 30.5, while the institutional rate again without CVTC becomes 23.6. The odds against observing this difference in rates are only 3:1, not at all statistically significant.

Yet this comparison is not representative of what a system of supports in the community would entail. Those requiring palliative care in a NF would be at least as likely to move from a waiver slot or a community ICF/IID as from a center. Moreover, 4 of the 5 individuals requiring palliative care came from SVTC as it was downsizing toward closure. The likelihood that 4 of 5 would come from just SVTC by chance has odds of 20:1 against. Thus, there must have been other individuals under palliative care who lived their last days in one of Virginia's centers. For this reason, *the 5 palliative care deaths at NFs should be counted as representative of what one would expect in a future community-based system of supports.*

5. Comparison of All Centers with All Community Settings

It is useful to consider the simple assumption that all those in centers, including CVTC, should be compared with the fate of all those moving out of centers into the full spectrum

of community settings. In this comparison, the mortality rate across all centers is 30.3, while that for all who left centers is 39.6. The odds of this occurring at random are only 4:1, a statistically indistinguishable difference. But this case ignores the much higher mortality rate at CVTC that artificially biases the comparison.

Data Alignment and Consistency

Table 2 shows the data in white boxes and calculated numbers in shaded ones. The DBHDS provided the SB627 Work Group with the number of deaths for each center over the period October 2011 through June 2014, the census at each center for July of 2011, 2012, 2013 and 2014 as well as the palliative deaths at NFs. Note that the difference between mortality counts beginning in October 2011 and census dates from July to July require interpolation to estimate the census on October 2011. These data were, however, sufficient to estimate the number of individuals transitioning from each center for those same time periods and support an analysis posted on the SB627 website. Subsequently, DBHDS provided the Regional Quality Council a census of those discharged from each center, returned to each center, transferred to other centers, or moved into NFs or SFs for the periods October 2011 to July 2012, FY 2013, and 2014. Thus, these latter data are restricted to only people with the privileges to see RQC data.

Unfortunately as Table 2 shows, there are some minor inconsistencies or gaps in these data. First, the simple interpolation to estimate October 2011 census yields numbers that imply discrepancies between the estimated number of deaths and the actual reported values, hence each center's October 2011 census was adjusted to close those gaps. Still, the estimate for deaths among those originally at CVTC falls 2 short while the estimate for NVTC falls 1 short. Possibly there were unreported admissions during these time periods? The other discrepancy is in the timing of deaths at SVTC. Balancing the totals for all deaths also implies "negative deaths" during FY11 and FY12. Table 2 represents this inconsistency in a manner that biases against the hypothesis that the community has a higher mortality rate hence strengthening confidence in the findings.

Statistical Analysis of Palliative Deaths

This analysis clarifies an important point about the events surrounding the closure of Southside Virginia Training Center, and it raises other important questions. Over the 2 and $\frac{3}{4}$ years from October 2011 and July 2014, four individuals discharged from SVTC died at a Nursing Facility while under palliative care. During this time period and among all the other centers, only one other individual died after discharge to a NF under palliative care, a person from SEVTC. This analysis estimates the likelihood that if there were only five palliative deaths in this time period that four would occur among those discharged from the one center that closed. Anticipating the result of this analysis, that such an event is quite unlikely, this paper explores the implications of this finding.

What is the probability that four of five palliative deaths at NFs were among those discharged from SVTC? To calculate this probability, first exclude CVTC since it has a Skilled Nursing Center on campus and any palliative care deaths would likely occur there. Thus, any discharges to a NF for palliative care death would be from one of the remaining three centers (NVTC, SEVTC, or SWVTC). Assuming that the likelihood of a palliative death at any center is proportional to its fraction of the total Training Center census, all of the possible outcomes can be expressed as follows:

$$1.0 = (p_{svtc} + p_{nvtc} + p_{sevtc} + p_{swvtc})^5.$$

Table 2. Census and Mortality Data for the Period October 2011 thru June 2014

Populations	Jul-11	Oct-Adj.	Period of Tracking Deaths					Reported Deaths	Person-Years
			Oct-11	Jan-12	Jul-12	Jul-13	Jul-14		
CVTC Census	381	10	381	357	342	301	288	41	887
TC Transfers			0		0	0	18		
Cumulative Discharges			0		20	45	69	4	
Cumulative returns			0		0	0	1		
CVTC Community			0		20	45	68		97
Estimated Deaths			0		19	35	43	45	
SVTC Census	242	-6	225	224	197	114	0	5	371
TC Transfers			0		0	0	-20		
Cumulative Discharges			0		40	121	234	10	
Cumulative returns			0		2	3	4		
SVTC Community			0		38	118	210		256
Estimated Deaths			0		-10	-7	15	15	
NVTC Census	157	1	157	152	153	135	106	12	381
TC Transfers			0		0	0	2		
Cumulative Discharges			0		0	14	40	2	
Cumulative returns			0		0	0	0		
NVTC Community			0		0	14	40		34
Estimated Deaths			0		4	8	13	14	
SWVTC Census	181	2	181	174	173	156	144	10	447
TC Transfers			0		0	0	0		
Cumulative Discharges			0		0	15	30	0	
Cumulative returns			0		0	2	3		
SWVTC Community			0		0	13	27		27
Estimated Deaths			0		8	12	10	10	
SEVTC Census	123	-5	113	111	104	84	75	3	255
TC Transfers			0		0	0	0		
Cumulative Discharges			0		4	24	33	2	
Cumulative returns			0		0	0	0		
SEVTC Community			0		4	24	33		44
Estimated Deaths			0		5	5	5	5	
Non-CVTC Census	703	-8	676	661	627	489	325	30	1,454
Cumulative Discharges			0		44	174	337	14	
Non-CVTC Community			0		42	169	310		361
Estimated Deaths			0		7	18	43	44	
Total TC Census	1,084	2	1,057	1,018	969	790	613	71	2,341
Cumulative Discharges			0		64	219	406	18	
All Community			0		62	214	378		457
Estimated Deaths			0		26	53	86	89	

Jul-11, Jul-12, Jul-13, and Jul-14 Training Center census data and deaths were provided to the SB627 Work Group by DBHDS.

Source of Jan-12 data: "Plan to transition individuals from state training centers to community-based settings," DBHDS, February 13, 2011.

Jul-11, Jul-12, Jul-13, and Jul-14 TC Transfers, TC discharges, and returns were provided to the Region II Quality Council.

The footnote to these data suggest that the period begins Oct-11 as with the mortality data.

Six individuals were discharged from SEVTC during FY-11 but not included in source data, hence 4 estimated.

The gray numbers have been calculated from the raw data:

Oct-11 baseline census for centers begins with an interpolation between Jul-11 and Jul-12 data to reduce the discrepancy between estimated and actual deaths.

The cumulative community census is the reported discharges minus transfers and returns to the TC.

Estimated deaths are the difference between the Oct-11 baseline census minus the TC and community censuses.

The Person-Years of exposure to mortality is the sum of the average censuses for FY-12 and FY-13 plus 3/4ths of a year time the average census from Oct-11 to Jul-12.

Minor inconsistencies remain:

The actual deaths exceeded estimated ones by 2 in the SVTC region and by 1 in the NVTC region.

Where there admissions that were not reported with the other data?

Matching the number of deaths at SVTC implies negative estimated deaths for the first two periods.

This discrepancy increased the calculated cumulative census by 4%, which decreases the calculated mortality rate and statistical significance.

This expression states that it is certain, of probability 1.0, that all possible patterns of five deaths, distributed across all of the four centers (excluding CVTC) in proportion to their

respective fractions of the state census, $p_{center\ name}$, would be the sum of those fractions, which equals 1.0, raised to the fifth power representing the five deaths.

The chance that four or more of the deaths during palliative discharge to a NF would occur among those from SVTC as a random event would then be:

$$P_{4_at_svtc} = p_{svtc}^5 + 5 \cdot p_{svtc}^4 \cdot (p_{nvtc} + p_{sevtc} + p_{swvtc}).$$

Since SVTC had 231 residents at the beginning of the period, while all of the centers excluding CVTC had 684, $p_{svtc} = \frac{231}{684} = 0.337$, and for the others, $p_{all_others} = 0.663$.

Finally, the probability of observing four or more from SVTC occurring at random is:

$$P_{4_at_svtc} = 0.337^5 + 5 \cdot 0.337^4 \cdot 0.663 = 0.0473.$$

This is equivalent to odds against of 20:1, which is statistically significant by academic standards.

The most plausible explanation of this finding is that all other Training Centers had comparable numbers of palliative care deaths on campus but without formal transfer to a NF. These deaths show once again that center residents are a very vulnerable population and deserve special attention, protection during any transition, and ongoing vigilance when in the community – along with all others already in the community with similar vulnerabilities.