Statistical Analysis of Training Center Downsizing and Closures: Opportunities and Necessities

The Need for Statistical Analysis

The ongoing downsizing and closure of Virginia's Training Centers offers a unique opportunity to evaluate the importance of many of the various risk factors facing people with Intellectual and Developmental Disabilities and especially those with extraordinarily high vulnerability to mortality. Analysis of this natural social experiment may be necessary if one is ever to identify and evaluate the value of systemic qualities of a system of supports, qualities such as integration of direct support and professional staff, timely response to symptoms and problems, continuity of direct care staff, and transportation barriers. Possibly most important of all is that analysis of this transition based on the Settlement Agreement requirement to track the outcomes for those who were in Training Centers is FY2012 provides a stratified data set consisting primarily of individuals with intense medical needs and behavioral challenges. It is among this population that the characteristics of quality in a system of supports become most evident – a knowledge that can be extended to help all those with even less challenging conditions and to recognize opportunities for cost savings.

There are by now 7 years of data to support statistical analyses of trends, patterns, and problems arising from the transition of those Training Centers to community settings. Most likely the Managed Care Organizations will assemble consolidated data records on each individual across service settings and cost areas, and this creates another opportunity for the MCOs and the DBHDS to work together to create a statewide consolidated data set to support analyses in order to monitor quality, improve supports to individuals, and save money.

In principle, comparative statistical analysis is a particularly simple and powerful tool for revealing the trends and patterns as required by the Settlement Agreement[1] as well as understanding the underlying factors to enable DBHDS to improve and sustain favorable outcomes:

- Comparisons over several years are sensitive to periods of elevated risk such as transition between systems of supports and are probably the only way to detect and understand trends.
- Comparisons among regions of the commonwealth are sensitive to differences in local conditions especially the availability of natural supports and unique methods of support delivery. For example, transportation effort and time can be a significant factor in cost and delays in accessing supports yet transportation challenges differ by region.
- Comparisons among settings, e.g., Training Center, nursing home, community ICF/IID, group home, and other less restrictive environments, must certainly be sensitive to systemic effects mentioned above. Systemic factors can offer broad improvements and savings; for example, in New Jersey, a more integrated system reduced both emergency room visits and hospitalizations by more than half.[2]
- Comparisons among individuals with different levels of need, characterized by, for example, waiver level of support, SIS scores, or the known short list of causes of most deaths, must certainly be sensitive to individual differences. In addition to

[1] See Sections V.B, V.C.5, and V.D.2.a.

[2] Kevin Walsh, private communication.

complementing the lessons gleaned from the Mortality Review Board, stratification of those in the system of supports by degree of risk of mortality or other forms of harm enhances the statistical sensitivity to the changes that increase or decrease harm.

Stated in another way, statistical analyses, especially comparisons, appear to be a *necessary* policy and support management tool in order to:

- Sustain the supports and well being of this most vulnerable minority of those with IDD by:
  - Identifying and tracking this minority among the majority of others with IDD.
  - Establishing and maintaining a baseline of expectation for quality supports.
  - Demonstrating the comparability of care in the spectrum of community settings.
- Understand the contribution of systemic factors for quality and cost savings.
- Identify trends, patterns, or problems within the system of supports.
- Identify and validate indicators to guide quality management.
- Make a persuasive case to the public and legislators concerning the necessity of sustaining supports for those who are most vulnerable and, more generally, for all of those with severe challenges as a result of their IDD and associated complications.

Some data are already at hand to illustrate the potential for statistical analyses to both improve the system of supports or to detect and diagnose otherwise unnoticed problems. The remaining sections of this paper explain key findings graphically or by tabular summary. Some highlights are the following:

- About 10 percent of those receiving supports have x3 to x4 or more the mortality risk relative to the normal adult population, while half those with supports experience only about x1.1 or less the normal rate. This is true in both community and institutional settings. *Hence this exceptionally vulnerable population warrants special attention to detect possibly serious changes that would be missed if averaged with the majority*.
- In Virginia since July of 2011 and the Settlement Agreement, mortality rates have increased significantly among those who either remain in or were in Training Centers. *Hence there appears to be either a surge of mortality in transition or a slippage in the efficacy of supports – either of which warrants explanation and remedial action*.
- Residents and former residents of CVTC experienced a much higher mortality rate than residents of other centers. This excess mortality was 69 percent higher in 2011 and remained 58 percent higher from FYs 2012 thru 2017. These discrepancies are greater than chance at the 95 percent level of confidence even if they were to occur at any of the five regions. *Hence more detailed regional comparisons are warranted to explain these known differences and determine whether those differences are intrinsic to some regions.*
- According to the data from an exhaustive California study covering the period from 1985 - 1994, the analysis performed for this paper showed that the fraction of those experiencing a mortality rate greater than a chosen amount declines exponentially with the chosen amount. This was true for two both of distinct systems of support, one with a much greater mortality rate than the other for individuals with identical risk factors. The statistical fit to the exponential decline is so precise as to suggest it is a universal *mathematical* feature for those in any system of supports for IDD. *Hence if demonstrated to be true for Virginia, this relationship provides valuable guidance for the design and calibration of statistical studies, especially for the stratification the population*.

- The California study also compared mortality rates for two distinct systems of support according to their respective outcomes for individuals with identical intrinsic risk factors. Those factors were limitations in mobility or self-care skills. Although these systems were the community versus state institutions, this analysis relies only on their being different to demonstrate important findings. At that time in California, the "community" system had mortality rates over 70 percent higher. The key point of this comparison is not to rehash community versus institutional support, but rather to underscore the possibility that two distinct systems of supports can yield even identical exponential declines with increasing mortality rates and have *identical average mortality rates,* yet one system can produce a mortality rate much higher than the other for those with comparable intrinsic risk factors. *Hence as indicators of quality, analysts must stratify data according to intrinsic risk factors to see these differences and not rely on average mortality rates or the exponential decline of population fraction with higher mortality rates*.
- These findings from the 1980's and 90's are particularly relevant to the design of statistical analyses today. Back then, functional factors such as mobility and self-care explained the extraordinary mortality risks experienced by a minority, but today many people entering the system of supports for those with IDD have primarily behavioral challenges such as autism. Also, the overall average mortality in the California study was sensitive to the small fraction of those with normal mortality rate, while today in Virginia 1,700 additional people from the urgent waiting list will finally be given waiver supports, many of whom now require state supports as their family care givers age. Thus, it is even more necessary to appropriately stratify Virginia's population of those receiving support to avoid being misled by average mortality rates as an unreliable indicator.

Description of Findings Based Upon Available Data

There are data at hand that already reveal some of the promise and necessity of system-wide statistical analyses. This section summarizes the findings from these data that address one of three broad topics: the much greater vulnerability to mortality for about 10 percent of those with IDD, a more precise analysis of the mortality time series for each Training Center region during the first 6 years of the Settlement Agreement, and a reanalysis of the exhaustive California data set from the 1980's and 90's that illustrates what appear to be canonical patterns that most likely apply to our experience here in Virginia today.

Rather than burden the reader with mathematical derivations, these will be provided upon request. This summary presents its analytical results as a discussion of summary tables and graphs.

A Vulnerable Minority

Two distinct data sources reveal that a small minority of those receiving supports for IDD has an exceptionally high risk of death. Then a contrived simple arithmetic example illustrates how important it is to report on this minority's outcomes separately as a stratified population if DBHDS is to detect significant declines or improvements in well being among this minority.

Who's at risk by how much?

Just before the Settlement Agreement, Virginia reported its 2011 census and mortality data to the University of Minnesota.[3] At that time, those in Training Centers were only 10.1 percent of all recipients of supports for IDD, yet that minority had a mortality rate 4.3 times greater than adults in the normal population; see Table 1. Much earlier in the national trend from center-based to waiver supports, an exhaustive study of California analyzed data on all community residents during the period between 1985 and 1994.[4] This reanalysis was able to compute that the most vulnerable 10.1 percent of this California population had a mortality rate 4.1 times the normal population in remarkable agreement with Virginia. By contrast, the less vulnerable 50 percent of the California population had a mortality rate only 1.1 times greater than the normal population.

Table 1. The Relative Vulnerability of the Most Vulnerable Strata

	Overall Recipient Person-Years			Vulnerable 10 Percent Strata			
Place	Time Period	All Recipients	Vulnerable Strata	Deaths	Percent of Recipients	Mortality Rate per 1,000	Times Normal Rate**
Virginia	2011	10,629	1,069	37	10.1%	34.6	4.3
California*	1985-1994	112,748	11,387.5	373.2	10.1%	32.8	4.1

Virginia results reported by the University of Minnesota at: http://rtc.umn.edu/risp11
California results from 1985 - 1994 reported by Strauss et al., 1998.
* California 1985 - 1994 recipients and are those in the community for the period. Person-years and deaths are for the upper 10.1 percent of community residents.
** The normal death rate for adults is nominally 8 per 1,000 per year.

How many excess deaths must occur to detect a problem?

For this vulnerable 10 percent minority, how many more deaths than the expected annual number would there have to occur in Virginia before a statewide statistical tool could detect a statistically significant excess? In particular, how important is it to track the most vulnerable 10 percent of those receiving supports as a separate stratified class? To gain insight into these questions, compare two alternative scenarios: one combining everyone into one class versus another that stratifies the most vulnerable into a separate class. The solvable analytical question is then, how many excess deaths would be to detect an increase in the mortality rate at the 95 percent level of confidence?

Since the California study reported a statewide mortality rate for the community of 16 per 1,000 and Table 1 shows that the most vulnerable 10 percent has a mortality rate of over 32 per 1,000, these rates offer a reasonable basis for comparing two scenarios for a state similar to Virginia as shown in Table 2. In the first scenario, all 10,000 receiving supports are combined into a single class with 160 deaths per year, and it would take 21 more deaths in a single year to exceed a 95% level of confidence threshold of detection. If all of these were among the most vulnerable, this would be a 66 percent increase. Over 2 years, it would take 29 excess deaths or a sustained 45

[3] Sheryl Larson, Patricia Salmi, Drew Smith, Lynda Anderson, and Amy Hewitt. "Residential Services for Persons with Intellectual or Developmental Disabilities: Status and Trends Through 2011," National Residential Information Systems Project (RISP), University of Minnesota, 2013. ONLINE: http://rtc.umn.edu/risp11.

[4] David Strauss, Theodore Kastner, and Robert Shavelle. Mortality of Adults With Developmental Disabilities Living in California Institutions and Community Care. 1985 - 1994, *Mental Retardation*, Vol. 36, No. 5, 360-371, October 1998.

percent increase. However, the expected statistical fluctuations for the less vulnerable 9,000 would be 11.2 deaths per year or 15.9 deaths total for 2 years. These fluctuations are nearly half the necessary excess and could delay detection. With many new waivers now coming available in Virginia, the overall average mortality would be even less predictable.

Table 2. Comparison of Detectable Excess Mortality for Two Scenarios: Combined versus Stratified

Comparison		Baseline Expectation			1 Year Detection		2 Year Detection	
Scenario	Strata	Person-Years	Mortality Rate/1,000	Deaths	Excess Deaths	Annual Increase	Excess Deaths	Annual Increase
Combined	All Together	10,000	16.0	160	21	66%	29	45%
Stratified	Upper 10%	1,000	32.0	32	9	28%	13	20%
	Lower 90%	9,000	14.2	128	11.2	--	15.9	--

This assumes a detection threshold at which deaths exceed expectations at the 95% level of confidence..
Since expected total mortality is 160 deaths for 10,000 person-years, this implies 160 - 32 = 128 deaths for the lower 90%
Note that the "excess deaths" for the lower 90% represents the expected fluctuation in deaths for that strata.

By contrast, first stratifying and then analyzing those who are most vulnerable as a separate class would reduce the excess deaths necessary to detect a significant increase in mortality to only 9 over 1 year and 13 over 2 years. These excesses are only 43 or 45 percent of the thresholds of detection without stratification, and represent 12 fewer lives lost over 1 year and 32 fewer lives lost over 2 years respectively.

How can the vulnerable minority be stratified for those in the community?

Given that there are community residents with vulnerabilities as high as former Training Center residents, it is critically important to identify the risk factors that enable analysts to stratify the community population. Comparison with the Training Center population with its detailed characterization of health promises to be an invaluable tool for identifying and validating these risk factors. Those risk factors might then be associated with readily available characteristics of the individuals receiving services, e.g., the SIS especially Section 3 Parts A and B, the level of support given the individual, or the known leading causes of mortality. And finally, these characteristics can be found for everyone receiving services to enable stratification.

At NVTC in 2011, there were detailed diagnoses of each individual by condition and limitations to daily living.[5] For example, on average residents had 2.5 conditions and 4.4 limitations on daily living. The most prevalent conditions were behavioral disorders (68%), Epilepsy (56%), and psychiatric disorders (49%), while the most prevalent limitations were cannot dress oneself (89%), cannot use the toilet without assistance (89%), and cannot feed oneself without assistance (87%). This was clearly a stratified population with a high degree of disability and associated risk factors.

Overall Mortality Trends in Virginia

This analysis offers important refinements over the previous crude estimates for the 6-year time series spanning the period form July 2011 thru July 2017. These data include the known census for each Training Center in July of 2011 and the number of deaths among those in each in of these regional populations for each of the 6 years. These data combine deaths in centers and the community into one number per year.

Since the initial population declines as some people die, this analysis calculates the expected number of deaths for each successive year based upon the assumption of a constant mortality rate

[5] Mark Diorio, NVTC Director. "NVTC Presentation to Senate Finance Committee," December 5, 2011.

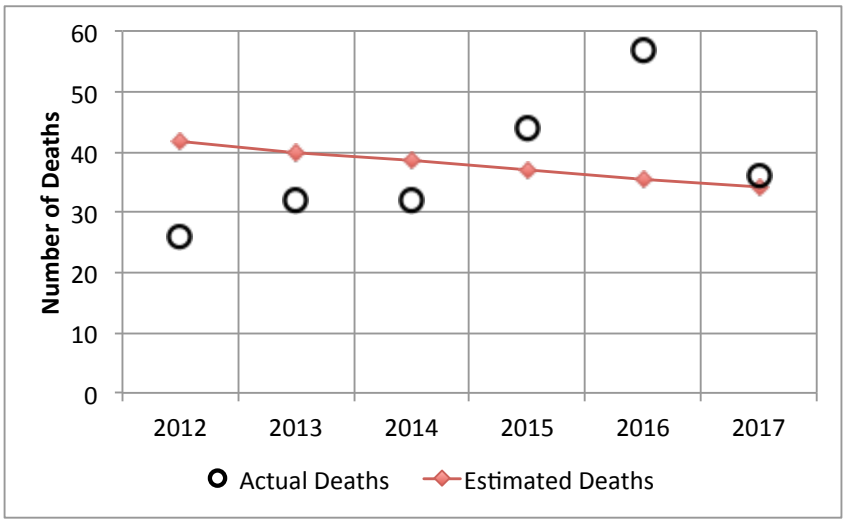
throughout the time period. Comparing the actual mortality to the expected mortality enables a calculation of the odds that the actual pattern would occur by chance if the mortality rate was in fact constant. If the resulting odds are less than 20:1, the hypothesis that the rate was constant is rejected as implausible.

Is the statewide time series consistent with a constant mortality rate?

Figure 1 shows the expected number of deaths statewide if the mortality rate were in fact the computed constant value of 39.3 per 1,000. Comparing actual to expected number of deaths reveals several significant findings:

- The actual pattern is inconsistent with a constant mortality rate, odds against 2,800:1.
- The excess 21 deaths in 2016 are *unexpectedly large for any year,* odds against 640:1.
- The odds against the last 3 years being equal to the prior 3 years are 16,700:1, clearly demonstrating a real upward trend in mortality rate.
- For the first 3 years, the average mortality rate was about 29 per 1,000 per year, but this rose to 50 per 1,000 during the last 3 years – an increase of 71 percent. But will this eventually prove to be a transient or rather new steady state?

Figure 1. All Deaths Among the Survivors of the Original Training Center Residents by Year



How do the five regions compare?

First, compare the average mortality rate for each Training Center individually; see Table 3:

- Over the period and for the CVTC population, their mortality rate of 51.9 per 1,000 per year far exceeded the combination of those from the other centers, a rate of 32.8 per 1,000, so the CVTC population suffers a 58 percent higher rate than the others.
- Only the CVTC population is statistically inconsistent with all others even considering the 1:5 odds for choosing any center at random, odds against of 31:1.
- These differences were evident back in in 2011 before the Settlement Agreement as CVTC had a mortality rate of 58.5 per 1,000 compared to an average of 34.6 for all five centers, which was then 69 percent greater than the average. Even in 2011, the odds against any center deviating this much from the others was 30:1.

- Table 3. Mortality Rates for Each Training Center Region and the Odds of Being Consistent with the Other Centers

Training Center	2011 Census	2011 - 2017 Deaths	Constant Rate/1,000	Unique Odds**	Any Center Odds***
CVTC*	381	102	51.9	154	31
SVTC*	241	47	36.2	2	0
NVTC	156	33	39.6	1	0
SWVTC	181	31	31.3	4	1
SEVTC	122	14	20.3	44	9
Total	1081	227	39.3		

* In 2014, about 20 residents moved from SVTC to CVTC.

** Unique Odds are from a Fisher Exact Test comparison to all other centers.

***These odds take into account any of the five centers could deviate.

How do the time series vary for each region taken separately?

Now consider the time series for each center population fit to its own constant average:

- Only NVTC significantly deviated from an hypothesized constant mortality across the 6 years, odds against 37:1. Specifically in 2016, 11 deaths occurred while only 5.2 were expected, a significant deviation no matter which year it occurred, odds against 29:1.
- CVTC and SVTC both had excess mortality in the last 3 years compared to the prior 3 years, odds against 100:1 and 21:1 respectively.
- If one combines all five centers into a 30-year series, the actual pattern of deaths deviates from the expected pattern, odds against 57:1.

How do the regions compare if they all had a common constant mortality rate?

Here each center was expected to have the common statewide average mortality rate of 39.3 per 1,000 person-years of exposure:

- CVTC now deviates from the common expected pattern, odds against 53:1. Note that the last 3 years had an excess of 22.4 deaths above the expected 37.6 deaths, 68 percent higher.
- NVTC still deviates from the common expectation because of the excess in 2016, odds against 38:1.
- SEVTC by contrast is significantly below the common average, odds against 20:1.
- Comparing the first 3 years to the latter 3 years reveals that four centers significantly deviate from the common expectation, odds against of 3,700:1 for CVTC, 22:1 for SVTC, 28:1 for SWVTC, and 55:1 for SEVTC (here again because of its lower mortality rate).

These findings indicate places and times where DBHDS might look in more detail to understand the reasons for the deviations and possibly learn ways to improve the system of supports.